DETERMINANTS OF PERCEPTION AND WILLINGNESS TO UPTAKE PREMARITAL SCREENING TEST FOR SICKLE CELL DISEASE AMONG HEALTH SCIENCES UNDERGRADUATE STUDENTS IN DAR ES SALAAM, TANZANIA

INDO NDAIGEZE

A DISSERTATION SUBMITTED IN PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR THE DEGREE OF MASTER OF SCIENCE IN PUBLIC HEALTH OF KAIRUKI UNIVERSITY

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CERTIFICATION

It is hereby certified that the undersigned have read and hereby recommend acceptance by Kairuki University, a dissertation titled: ***"Determinants of Perception and Willingness to Uptake Premarital Screening Test for Sickle Cell Disease Among Health Sciences Undergraduate Students in Dar Es Salaam, Tanzania"*** in partial fulfilment of the requirements for the Degree of Master of Science in Public Health.

Supervisors	**Signature**	**Date**
Prof. Titus Kabalimu	_____	_____
Prof. Moshi Ntabaye	_____	_____

DECLARATION AND COPYRIGHT

I Indo Ndaigeze, declare that this dissertation is my effort and original work and that it has not been presented and will not be presented to any other University for a similar degree or any other academic award. Being a student researcher, enrolled at Kairuki University, I understand that plagiarism is a serious offense, and therefore confirm that the contents of this research are purely my production.

Signature: ..... Date: .....

ACKNOWLEDGEMENT

I am deeply grateful to the Almighty God for His unwavering guidance and blessings throughout this research endeavor. His grace has enabled me to overcome challenges and complete this work successfully. I would like to express my sincere gratitude to my employer Kairuki University for granting me study leave, financial assistance and permission to conduct this research. I am indebted to my research supervisors, Prof Titus Kabalimu and Prof. Moshi Ntabaye, for their unwavering patience, motivation, and guidance. Their expertise and encouragement have been instrumental in shaping this dissertation. I am also grateful to Prof. Godwin Ndossi, Prof. Semali and Dr. Optat Kajuna for their invaluable contributions and support in completing this research.

DEDICATION

I would like to dedicate this dissertation to my beloved husband, Mr. Edward G. Mushi and my daughter Elsa, whose unwavering love and support have been a constant source of strength. I am also grateful to my parents, Mr. and Mrs. Jumanne Ndaigeze, and my sisters, Tettah and Sarah, for their continuous encouragement, support, and prayers. I also extend my gratitude to my fellow classmates for their cooperation, assistance, and support throughout my studies. To those not mentioned by name, thank you for your encouragement and contributions to my success. May the Almighty God bless you all.

ABSTRACT

Background: Sickle cell disease is a serious genetic disorder with a significant global burden. The significant burden of SCD in Tanzania and the substantial economic, psychological and social costs, highlights the significance of premarital genetic screening for sickle cell disease (SCD) for timely diagnosis as well as for identifying carriers of SCT.

Objectives: The objective of the was study to assess the determinants of perception and willingness to uptake premarital screening test for sickle cell disease among health sciences undergraduate students in Kairuki University, Dar es Salaam Tanzania.

Methodology: An analytical cross-sectional design was used among 448 undergraduate students (aged 18-35 years) who were selected using stratified random sampling technique. A structured questionnaire was used to collect data via Google forms. Data was analysed by using SPSS version 25 and presented as Tables and Charts. Bivariate logistic regression was employed to examine the relationship between multiple independent variables and dependent variable (perception).

Results: The study found out that more than half of the students (57.3%) had good perception regarding premarital screening and the majority agreed to uptake premarital genetic screening for Sickle Cell Disease. Respondents who received information from healthcare professionals had significant association with good perception.

Conclusions: In summary, over half of the respondents (57.24%) had a good perception of premarital screening for sickle cell disease. Most respondents had good perception on premarital screening and the influencing factor that has been

found appropriate information from healthcare providers. Moreover, a substantial percentage of respondents (92.2%) expressed their intention to undergo premarital genetic screening for sickle cell disease. This indicates a high level of awareness and a willingness to take proactive health measures prior to marriage, demonstrating a favourable attitude toward genetic screening.

Recommendations: The Ministry of Health, Community Development, Gender, Elderly and Children in collaboration with the Ministry of Education should develop a curriculum focused on educating the public about premarital genotype screening for sickle cell disease. This education should be delivered through various media channels, schools, health facilities, and public meetings to ensure that everyone in the community can participate in addressing and preventing sickle cell disease and is empowered to make informed choices in relation to genetic screening for Sickle Cell Disease before marriage.

Key words: Sickle cell disease, premarital genetic screening for SCD, informed choice

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ABBREVIATIONS AND ACRONYMS

BScN	Bachelor of Science in Nursing
BSW	Bachelor of Social Work
CDC	Centres for Disease Control and Prevention
EASTC	Eastern Africa Statistical Training Centre
HCP	Healthcare Professional
KU	Kairuki University
MD	Doctor of Medicine
MOHCDGEC	Ministry of Health, Social Development, Gender, Elderly and Children
PMGS	Premarital Genotype Screening
SCD	Sickle Cell Disease
SCTS	Sickle Cell Trait Screening
TCU	Tanzania Commission for Universities
WHO	World Health Organization

DEFINITION OF TERMS

Everyone with sickle cell disease shares the same gene mutation. A thymine replaces an adenine in the DNA encoding the ß-globin gene. Consequently, the amino acid valine replaces glutamic acid at the sixth position in the ß-globin protein product (Ingram, 1956). The change produces a phenotypically recessive characteristic. Most commonly sickle cell disease reflects the inheritance of two mutant alleles, one from each parent.

The final product of this mutation, hemoglobin S (HbS), is a protein whose quaternary structure is a tetramer made up of two normal alpha-polypeptide chains and two aberrant $ß^s$-polypeptide chains.

CHAPTER ONE

INTRODUCTION

1.1 Background

Sickle cell disease (SCD) is a group of red blood cell disorders caused by inheriting an autosomal recessive trait of a structural mutant variant of the normal adult haemoglobin (HbAA) in the erythrocytes (1). This disease is mainly genetically caused when one inherits a defective gene from both parents (2, 3). It is usually characterized by recurrent episodes of severe acute pain, stroke, acute chest syndrome, neuropathy, retinopathy, priapism, and avascular necrosis (4). Sickle cell trait occurs when a person inherits one defective sickle haemoglobin gene from one parent and another normal haemoglobin gene from the other parent. Thus, becomes a carrier of sickle cell disease and can therefore pass the haemoglobin defective gene on to their children (5). It is more common among people whose ancestors come from Africa, the Mediterranean region, the Middle East, and Central and South American, and Asian Indian origin or descent, but anyone can have sickle cell trait (6).

Sickle cell disease has been recognized as a global public health concern, with approximately 5% of the world's population carrying trait genes of haemoglobin disorders, predominantly sickle cell disease (7). This translates to, more than 300,000 births have sickle cell disease worldwide with the highest burden in low and middle-income countries, and most cases dying in their early years of life due to delayed diagnosis and treatment of complications of the disorder such as infections, chest syndrome and stroke hence accounting for a mortality rate of up to 92% (1).

The sickle cell disease burden is expected to rise by 2050, with approximately 400,000 children born with sickle cell disease annually. Countries like Nigeria, India, and the Democratic Republic of Congo account for half the global burden of sickle cell anaemia(8). Globally, Tanzania has the fifth highest number of sickle cell disease births annually; however, Tanzania has taken a great step in diagnosing and managing sickle cell disease, acknowledging its public health importance (9). To prevent genetic disorders including sickle cell disease, several preventive methods have been put in place including primary prevention such as pre-marital genetic screening and counselling (10, 11). Carrier identification and pre-marital genetic counselling focused on sickle cell trait carriers remain to be the most basic practical approach to reducing the burden of sickle cell disease in low-income countries (10). Premarital genotype screening provides a chance for individuals to be informed on their genetic predisposition to diseases as well as providing knowledge to prospective couples regarding the possible genetic characteristics of their unborn children (12). Universities in Tanzania mostly consist of unmarried youth who plan to get married and procreate in the future; therefore, are a good target population who can benefit from the relevant interventions towards prevention and /or controlling sickle cell disease especially if one is in love or plans to get married (10, 13-15). Despite the advancement in technology, there are still challenges to access and availability of sickle cell disease services such as premarital genotype screening for sickle cell disease (16). Insufficient knowledge and poor perceptions regarding sickle cell disease has been identified to be the catalyst for the development and spread of misconceptions and myths about the disease. With the present high sickle cell burden in Tanzania, still there are limited studies on youth's perception of premarital genetic counselling and screening for sickle cell disease in Dar es Salaam.

Therefore, the proposed study aimed to provide information on the perception of pre-marital genotype screening and counselling for sickle cell disease among undergraduate university students. This information will help the Ministry of Health and other stakeholders in planning interventions, policies, and programmes to intensify awareness campaigns on premarital genetic counselling and screening for sickle cell disease.

1.2 Problem statement

Sickle cell disease is a significant public health problem in many parts of the world, including sub-Saharan Africa, where it is the most common genetic disorder with an estimated 240,000 births annually (17,18). Despite various interventions to mitigate its impact, the implementation of preventive measures such as premarital genotype screening remains challenging (14). However, it is crucial to acknowledge that this screening program has the potential to greatly reduce the prevalence of SCD by informing couples about their carrier status the associated risks of having children with the disease (19). Individuals' willingness to participate in such screening programs is influenced by their perception and awareness of the disease severity (20). Previous research has shown some negative perceptions towards premarital genotype screening. A recent study conducted in 2024 at Muhimbili National Hospital in Dar es Salaam Tanzania found that many SCD patients had negative perceptions regarding genetic screening due to fear of stigmatization, religious and cultural beliefs (21). This gap among young adults leads to ill-informed decisions regarding marriage and potentially exacerbates the burden of SCD (3). However, in Tanzania there are limited studies assessing the determinants of perception and willingness to uptake premarital genetic screening for SCD particularly among youth.

Considering that many University students have plans for marriage and procreation, they represent a crucial target group that would greatly benefit from interventions aimed at preventing and controlling SCD. This research aimed to bridge the existing knowledge gap and provide valuable insights for the development of strategies to alleviate the burden of SCD in Tanzania. Therefore, this study focused on assessing the determinants of perception and willingness to participate in premarital genotype screening for SCD among undergraduates at Kairuki University in Dar es Salaam.

1.3 Study objectives

1.3.1 Broad objective

To assess the determinants of perception and willingness to uptake premarital screening test for sickle cell disease among health sciences undergraduate students in Kairuki University, Dar es Salaam Tanzania.

1.3.2 Specific objectives

1.3.2.1 To evaluate the perceptions of health sciences undergraduate students regarding pre-marital screening test for SCD in Kairuki University, Dar es Salaam.

1.3.2.2 To identify the factors associated with good perception towards pre-marital screening test for SCD among health sciences undergraduate students in Kairuki University, Dar es Salaam.

1.3.2.3 To assess the willingness of Kairuki University (KU) health sciences undergraduate students to uptake premarital screening test for SCD in Dar es Salaam.

1.4 Rationale of the study

The focus on undergraduate students arises from the recognition that they are at a critical moment in their lives, where decisions regarding marriage and family planning are becoming increasingly relevant. Consequently, it is imperative to assess the perception and willingness to uptake premarital screening for SCD among students. This information can identify gaps in awareness and understanding that may hinder the effective implementation of genotype screening programs. It can also potentially offer insights into targeted educational approaches that aim to promote knowledge and acceptance of genotype screening. Lastly, understanding the students' view can offer insights into cultural and social factors that may impact their perception about premarital genotype screening for SCD and their willingness to test and guide the creation of culturally sensitive communication strategies. This research targeted undergraduate students with the aim to enhance our comprehension of their perception and willingness to uptake premarital screening tests, aiding in the development of potent strategies to mitigate the burden of SCD in high prevalence regions.

1.5 Research questions

1.5.1 Broad research question

What are the determinants of perception and willingness to uptake premarital screening test for sickle cell disease among health sciences undergraduate students in Kairuki University, Dar es Salaam?

1.5.2 Specific research questions

i) What are the perceptions of health sciences undergraduate students regarding pre-marital screening for sickle cell disease in Kairuki University, Dar es Salaam?

ii) What are the factors associated with good perceptions towards pre-marital screening for sickle cell disease among health sciences undergraduate students in Kairuki University, Dar es Salaam?

iii) What is the proportion of health sciences undergraduate students who are willing to uptake premarital screening for SCD in Kairuki University, Dar es Salaam?

CHAPTER TWO

LITERATURE REVIEW

2.1 Overview of the literature in relation to premarital genetic screening

Premarital genotype screening helps to point out health risk factors that bring about genetic disorders such as sickle cell disease. It is one of the most effective ways of preventing genetic disorders. To reduce the high burden of sickle cell disease and break the sickle cell disease cycle, improved awareness, perception and knowledge on premarital genotype screening and counselling is one of the chief approaches to attain this purpose.

The people in sub-Saharan Africa bear a significant burden of sickle cell disease globally compared to other regions across the world. Within West Africa, there exists a disparity in the level of perception regarding this condition, as observed in a study conducted among the youth in Yaba, Nigeria. The findings from this study indicated that a majority of the respondents (80%) were knowledgeable of sickle cell disease and had positive perception (86%) about premarital screening for this condition. However, another study conducted among young tertiary students attending Federal College of Education in Kano, Nigeria reported that less than half (40%) of the participants possessed a good perception regarding premarital screening (22,23).

However, a research study carried out within the countries of Eastern Africa, specifically in Uganda, focused on students enrolled in a Ugandan university, revealed that a vast majority of the participants, accounting for approximately

93.64%, possessed a good knowledge and had good perception regarding both Sickle Cell Disease (SCD) and Sickle Cell Trait Screening (SCTS). This impressive outcome can be attributed to the fact that these students were in medical school, where they were exposed to lectures and gained first-hand knowledge through clinical practice regarding SCD (4).

A study carried out among students at King Khalid University in Saudi Arabia revealed that 73.4% and 69% of the students were knowledgeable of premarital genotype screening and its role in preventing genetic disorders. Additionally, it was observed that 95.2% of students perceived premarital genotype screening as important and expressed willingness to undergo the screening test (24).

Another study conducted in Saudi Arabia reported that 98.3% of the participants were familiar with premarital genotype screening; however, more than half (59%) of them exhibited poor perception and concern for inherited genetic disorders due to a lack of understanding about the screening process. Moreover, the study revealed that many participants obtained information about premarital genotype screening from their friends and colleagues rather than from healthcare facilities. Nevertheless, the study emphasized the necessity for increased awareness campaigns regarding premarital genetic screening, given the observed poor perception and lack of knowledge (25).

A subsequent investigation conducted in Egypt involving undergraduate students revealed that 53.9% of the respondents had good perception regarding premarital genotype screening, with about 74% of the respondents believing that PMGS is

important and useful. Media emerged as the primary medium through which the participants obtained information for students enrolled in both practical and theoretical faculties (26).

In a study conducted in Nigeria among final-year undergraduates, reported that almost all the participants (98.7%) knew about premarital genotype screening for sickle cell disease with the majority indicating that media (radio, television, magazines, and newspapers) and lectures or schools being the main sources of information. However, another study conducted among students attending federal College in Kano, Nigeria reported poor perception (60%) towards PMGS among the participants with majority (71.9%) of the Islamic religion respondents having a good perception towards PMGS as compared to the Christian respondents (68.4%) (23).

Another study conducted in Benin City, Benin to assess awareness and acceptability of premarital genotype screening of sickle cell disease among undergraduates reported that only 78.9% of the respondents had positive perception about premarital genotype screening and the majority reported media, lectures, seminars, and health facilities as the major source of information (10).

According to a study done in Khartoum, Sudan which assessed premarital counselling and screening awareness and perception among medical students reported that half of the study participants showed negative perception towards premarital genetic counselling, despite majority (71.3%) of the students believed PMGS is crucial. Within the same study, the commonest source of information being social media (49.6%) (27).

In Tanzania, a study conducted in Dar es Salaam among SCD patients, and their relatives reported a positive perception towards PMGS for SCT and recognized PMGS as beneficial. This may be due to the experiences of the emotional and physical struggles associated with SCD. This study concluded that participants perceived PMGS as beneficial and suggested for a designed screening programs targeting youths allowing them to know their haemoglobin genotype early before marriage. Despite these recommendations, studies to assess the perception towards premarital genetic screening among youth in Tanzania are still limited (21).

The willingness to participate in premarital genotype screening was found to be 70% according to the study conducted in Saudi Arabia among university students which assessed the perception of premarital genotype screening, however, there was reluctance in half of the participants in their willingness to take part in screening program despite majority knowing the importance of premarital genotype screening (24). Moreover, a study conducted among Saudi adults reported that the majority of participants (97.2%) were willing to undergo genotype screening, and they supported the idea of a compulsory premarital genotype screening with 98.8% of the participants agreeing to recommend premarital screening to others (25). A study done by Farahat et al in Egypt reported that 74% of the students believed that premarital screening for genetic disorders was useful with more willingness to uptake premarital screening of genetic disorders among practical students than theoretical students (26).

In sub-Saharan Africa, a study done in South-West Nigeria among final-year undergraduate students reported that the majority (92.3%) of the participants were

willing to opt for premarital genotype screening, with 94.7% of the participants agreeing that the screening reduced the incidence of SCD and recommended that it should be mandatory for every adult before marriage. Similarly, another study conducted in the Plateau State, Nigeria reported that majority of the participants (77.3%) were willing to go for premarital genetic screening (28).

Furthermore, a study done in Sudan reported low willingness (39%) to participate in premarital screening among students, with reasons for low willingness being due to lack of adequate awareness and knowledge (44.5%) on premarital screening programs for sickle cell disease and social and cultural factors (33%) (1). In Uganda, a study conducted to assess sickle cell trait screening in university students reported majority of the students were willing to participate in the premarital screening services and 82.3% agreed that it was important and beneficial and would encourage their partners to screen (4).

Studies have indicated various factors influence individuals' perception of premarital screening for sickle cell disease, including their age group, gender, and marital status (2). In the context of Saudi Arabia, research conducted by Faisal S.A. et al among university students revealed that individuals aged 25 years or older had a commendable positive perception regarding premarital screening, as compared to those below the age of 21 years (26). Additionally, concerning gender, marital status, and the nature of their college education, it was found that female students, married individuals, and students pursuing medical studies exhibited positive perception regarding premarital screening for sickle cell trait in comparison to their

male counterparts, unmarried individuals, and non-medical students respectively (23).

Similarly, a study conducted in Benin demonstrated that the highest level of knowledge was observed among participants aged 25-29 years, female respondents, and married individuals (2). Furthermore, in an analysis carried out among Nigerian young adults, both married and unmarried, it was noted that in terms of gender, female participants demonstrated a positive perception (60.8%) regarding Sickle Cell Disease and premarital sickle cell genetic screening, while their male counterparts exhibited a negative perception in 39.1% (29).

Another study conducted in Lagos, Nigeria, also revealed that various factors, such as the participants' age, educational level, employment status, and self-genotype awareness, exerted an influence on their level of knowledge concerning sickle cell disease and their perception towards premarital genetic screening for SCD (30). Specifically, as the participants' age and level of education increased, there was a corresponding increase in the number of individuals who possessed a good perception towards PMGS. Furthermore, it was observed that employed participants and those who possessed knowledge of their own genotype exhibited a good perception compared to their unemployed counterparts and those who were unaware of their self-genotype (31).

2.2 Description of the conceptual framework for the study

In the context of this study, the conceptual framework guided the understanding of the relationship between variables and how they influence each other. The

independent variables are factors that are believed to influence the dependent variable. Factors such as demographic characteristics which include gender, religion, academic program and year of study have been reported to influence the perception on SCD as well as individual's perception towards premarital genetic screening (PMGS) for SCD. In such that a factor such as year of study has been reported that the individuals at a higher education level have a good perception compared to those who were at a lower education level (30). Concerning the academic program, students in healthcare-related fields may have good knowledge of SCD and a good perception premarital genetic screening (25).

The source of information including factors such as formal education, media exposure, community outreach programs and family discussions have also been linked to affect the perception regarding premarital genetic screening (PMGS) for sickle cell disease. The students exposed to formal education such as biology and medical school are more likely to be exposed to accurate information concerning SCD and premarital genetic screening. Media exposure can also influence the knowledge and perception on SCD and premarital genetic screening. Exposure to community outreach programs can provide targeted education and address specific community needs. Family discussions can also be a source of information and influence personal beliefs on SCD and premarital genetic screening of this condition (28). Concerning the moderating variables, age may be associated with different levels of exposure to information on PMGS for sickle cell disease and life experience (25). Furthermore, cultural factors such as traditions, beliefs and norms can also significantly affect the individuals' perception of SCD and PMGS and willingness to uptake premarital screening for SCD. The study evaluated the perception and

willingness to do premarital genetic screening for sickle cell disease among undergraduate students, examined the influence of demographic characteristics, sources of information, and moderator variables on perception, and develop recommendations for targeted interventions to improve knowledge, perceptions and awareness. This is shown in Figure 1 below:

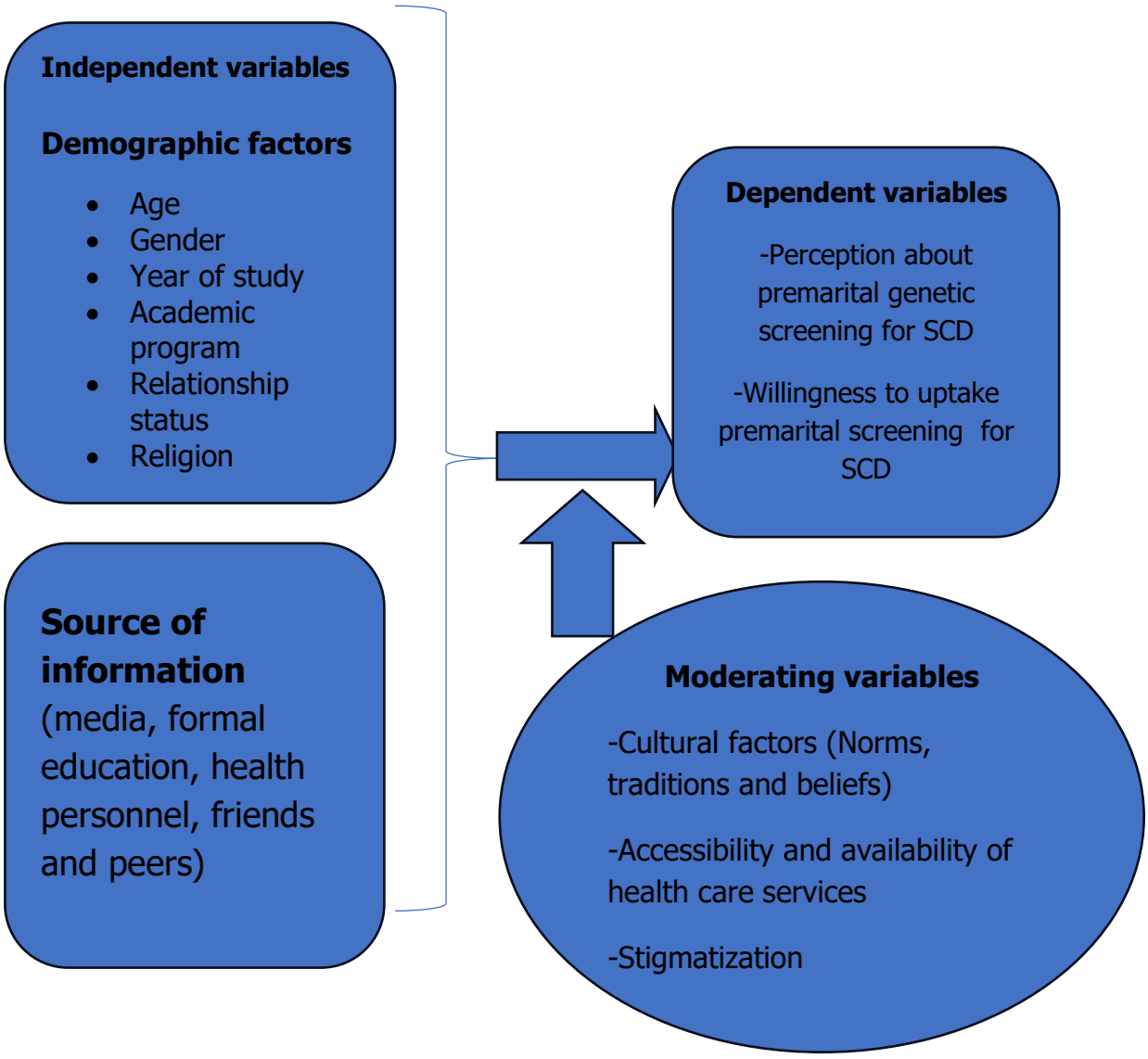

Figure 1: Conceptual framework for the study (Source: PI 2024).

CHAPTER THREE

METHODOLOGY

3.1 Study area and population

The study was conducted at Kairuki University (KU). KU is a private medical university located in Kinondoni Municipal Council, one of five administrative councils within Dar es Salaam region situated along the Indian Ocean coastline. Kinondoni borders the Ilala district to the South and Ubungo district to the North. The municipality has a population of 982,328 (474,825 males, 507,503 females) and harbors six Universities. KU is an accredited institution and offers postgraduate, undergraduate, along with diploma and certificate programs. The University's student body is comprised of 1,781 individuals (majority above 18 years old), including 1,141 females and 640 male students. This study area was selected purposively by considering time and budget constraints.

Table 1: Academic programmes at Kairuki University

Name of the academic programme	**Course name**	**Year of study**	**Student population**
Postgraduate programmes	Master of Medicine in Internal Medicine	3	26
	Master of Medicine in Surgery	3	10
	Master of Medicine in Obstetrics and Gynaecology	3	29
	Master of Science in Public Health	1.5	7
Undergraduate programmes	Doctor of Medicine (MD)	5	1,170
	Bachelor of Science in Nursing Degree (BScN)	3	243
	Bachelor's in Social work	3	40
Diploma and Certificate programmes	Diploma in Nursing	3	194
	Diploma in Social Work	1	45
Total			**1764**

The study population consisted of full-time undergraduate students at Kairuki University. Undergraduate students were included in the study because youths in universities are a good target population who will benefit more from the relevant interventions towards controlling of sickle cell disease (13).

The study population involved students from all courses in the undergraduate programme aged 18-35 years at Kairuki University.

3.2 Study design

The study utilized an analytical cross-sectional study design, a quantitative approach among consenting undergraduate students (aged 18-35 years) attending Kairuki University in Kinondoni Municipal Council during the study period. This design is suitable for identifying the students' perception and who are willing to participate in premarital screening for SCD and the associated factors for their perception towards premarital screening among students at a specific point in time.

3.3 Sampling technique

A stratified random sampling technique was used to obtain eligible respondents. In the first stage, stratification was performed to obtain the representative sample according to the course (MD, BScN, and BSW), and in the second stage stratification was done to obtain the representative sample of each year of study (first to fifth year for MD, first to fourth year for BScN, and first to third year for BSW). Third stage involved the stratification to ensure for gender composition across the study. The required sample size was then selected within each stratum using systematic random sampling method.

i.e. Stage 1: To obtain the representative samples in each course.

$$\text{Each course} = \frac{\text{Number of students enrolled in the selected course}}{\text{Total number of undergraduate students at the University}} \times n$$

Where n is the minimum sample size.

Stage 2: Stratification to obtain a representative sample for each year of study within the course:

$$X = \frac{\text{Number of students in each year of study in the selected course}}{\text{Total number of students from the selected course}} \times n_1$$

Whereby n_1 is the representative sample in the course.

Stage 3: To ensure balanced gender composition in each year of students

$$y = \frac{\text{Number of male and female students in the specific year of study}}{\text{Number of students in the year of study x representative sample in the year}}$$

Stage 4: To obtain the required sample size in each stratum by systematic random sampling. For example, for MD 1: Numbering of students in the students list was done from 1 to 92. To determine the sampling interval (k^{th}) for male students K^{th}= population size / desired sample size - K^{th}= 92/38 = 2 A starting point was determined by randomly selecting a number below 3.

Table 2: Number of students and gender in each year of study

Course and total number of students	Number of students in each year of study	Gender of students in each year of study
MD	Year 1 = 284	Male = 116
(n = 1170)		Female = 168
	Year 2 = 235	Male = 80
		Female = 155
	Year 3 = 245	Male = 116
		Female = 129
	Year 4 = 288	Male =128
		Female = 160
	Year 5 = 118	Male = 54
		Female = 64
BScN	Year 1 = 89	Male = 15
(n=243)		Female = 74
	Year 2 = 77	Male = 16
		Female = 61
	Year 3 = 47	Male = 9
		Female = 38
	Year 4 = 30	Male =11
		Female = 19
BSW	Year 1 = 18	Male = 4
(n=40)		Female = 14
	Year 2 = 13	Male =5
		Female= 8
	Year 3 = 9	Male = 3
		Female = 6

3.3.1 Sample size estimation

The sample size was calculated using the Open Epi calculator for the cross-sectional study design. A study conducted in Southwest Nigeria by Adesina et al reported 76.07% had good perception of premarital genotype counselling and screening (28). Using this prevalence (P=76.07%) and other assumptions such as a 95% confidence level (Z=1.96) and a margin error of 5%, considering 10% non-response rate, the calculated minimum sample size was 235 undergraduates. With a design effect of 2 the minimum representative sample size was 470 students.

This sample was distributed as shown in Table 3 below:

Table 3: The representative sample in each stratum

Course and representative sample according to course	**Representative sample according to year of study in the course**	**Representative sample according to gender in each year of study**
MD 378 students	Year 1 = 92 students	Male = 38 students
		Female = 54 students
	Year 2 = 76 students	Male = 26 students
		Female = 50 students
	Year 3 = 79 students	Male = 37 students
		Female = 42 students
	Year 4 = 93 students	Male =41 students
		Female = 52 students
	Year 5 = 38 students	Male = 17 students
		Female = 21 students
BScN 80 students	Year 1 = 29 students	Male = 5 students
		Female = 24 students
	Year 2 = 25 students	Male = 5 students
		Female = 20 students
	Year 3 = 16 students	Male = 3 students
		Female = 13 students
	Year 4 = 10 students	Male =4 students
		Female = 6 students
BSW 12 students	Year 1 = 6 students	Male = 1 student
		Female = 5 students
	Year 2 = 4 students	Male =2 students
		Female= 2 students
	Year 3 = 3 students	Male = 1 student
		Female = 2 students

3.4 Procedures for Data collection

3.4.1 Data collection tools

Data was collected using a pretested self-administered questionnaire using a Google form which focused on the objectives of the study. The Google form was shared to the study participants through their e-mails and social media (i.e WhatsApp). The questionnaire was in English language containing three sections namely section A, B and C.

Section A: This section consisted of seven options requesting the socio-demographic characteristics of undergraduate students at Kairuki University such as gender, age, religion, relationship status, program of the study, and year of study.

Section B: This section comprised of thirteen questions that assessed the individuals' perception regarding sickle cell disease and premarital genotype screening for SCD adopted from previous studies (3). The questions included, the perceived seriousness of SCD, regarding premarital genotype screening, questions included perceived benefits of PMGS, the perceived barriers to PMGS and sources of information regarding pre-marital genotype screening.

Section C: This section comprised of two questions to identify the participant's willingness to participate in premarital screening for SCD including if they would opt for pre-marital genetic screening, and if they would recommend others to screen for SCD.

3.4.2 Data collection methods

Three research assistants were recruited and trained on the study protocol, the aim of the study, and the data collection tool to assist in the data collection process for

this study. Before the data collection process was initiated, the questionnaire was pretested on 20 students at one course at the university and these students were not selected for the study. This pretest of the tool was done to verify that the questions were well understood, clear and brought out the intended information from the study population and evaluated the validity and reliability of the tool before use.

3.4.3 Eligibility criteria

Inclusion criteria

i) All Kairuki University currently registered undergraduate students aged 18-35 years.
ii) All undergraduate students who agreed to participate in the study.

Exclusion criteria

i) All undergraduate students who were ill, and not available during the study were excluded.
ii) All undergraduate students who were above 35 years.

3.4.4 Study variables

Dependent variables

i) Perception of premarital genotype screening for SCD.

Perception of pre-marital sickle cell screening in the context of this study referred to degree in which adult students have good or poor perception about premarital sickle cell screening which will enable them to make better choice of life partner.

Perception of premarital genotype screening was measured by using 13 questions including perceived seriousness of SCD, if they believe SCD premarital genetic screening is beneficial, perceived barriers to premarital genetic screening for SCD, sources of information regarding premarital genotype screening (media, friends, health personnel, lectures/seminars, and family), when should premarital genotype screening be done.

ii) Willingness to participate in premarital genotype screening for SCD.

This variable was measured by using a set of questions including; if the participant would opt for premarital genetic screening and if they would recommend the screening test to others or their partners.

Independent variables

Socio-demographic factors: these variables are characteristics of the participants that potentially influence their perception - Age: measured in years, gender: categorized as male and female, year of study: categorized as year 1, year 2, year 3, year 4 and year 5; Academic program: categorized as MD, BScN and BSW ; Relationship status: categorized as single and engaged; Religion: categorized as Christian, Muslim, and other; Sources of information on premarital genotype screening for SCD; this variable identifies where the students heard of premarital genotype screening, potentially impacting their perception examples might include media, formal education (seminars/lectures), family discussion, community health personnel, friends, and peers.

Moderating variables - Cultural factors (including traditions, beliefs and norms), ability to access and use health care services and stigmatization.

3.4.5 Ethical considerations

The areas of ethical concern in this study were mainly issues with privacy, confidentiality, and anonymity. Privacy was maintained during the data collection process and each participant was free to write his/her own opinions. For confidentiality purposes and anonymity, a coding system was used to identify participants therefore, no names, student identification numbers or any form of personal identification was used in the questionnaire. Furthermore, within the google form a section was dedicated for informed consent for all eligible participants. This section provided a concise overview of the research and participants were informed of the aim of the study and encouraged to seek clarification from the researchers whenever the information is unclear. A required checkbox question was included stating "I have read the informed consent document and agree to participate in this study". The respondents who consent were then directed to the survey questions. Participation in this study was voluntary and there were no penalties for those who were not willing to participate. Moreover, the participants were allowed to exit the study at any time they wish to even after they have consented. The information obtained was only used for this study and participants' information would not be shared with other people who were not part of the study. Furthermore, for students who were engaged during the study and faced challenges with their partner, they were linked with a relationship counsellor who provided emotional and psychological support according to their need.

Ethical clearance

Ethical clearance to conduct the study was obtained from the Institutional Research and Ethics Committee of Kairuki University and further permission was sought from the Kairuki University administration.

3.4.6 Reliability and validity of the data collection tool

Reliability means that the results should be consistent each time the test is administered or when different investigators obtain similar responses from participants.

Validity refers to how accurately an idea is measured and whether the instrument covers all relevant content. To ensure the reliability of the quantitative data collected through Google forms, the research implemented several measures. Overall, all three scales exhibited good to acceptable internal consistency, indicating that the items within each scale were measuring their respective constructs reliably. This reliability was essential for ensuring that any conclusions drawn from the analysis of these variables were based on sound measurement. In practical terms, our study could confidently use these scales to understand participants' perceptions regarding the seriousness of sickle cell disease, the benefits of premarital genotype screening, and the barriers to screening and the discussion below shows the findings to both scales.

Table 4: Results of the Reliability Test

Questions	Number of Respondents	Cronbach's Alpha	Number of Items
Participants perceived seriousness of Sickle Cell Disease	448	0.751	5
Perceived benefits of premarital Genotype Screening	448	0.707	4
Participants perceived barriers to pre-marital genotype screening	448	0.724	4

Internal consistency was assessed using Cronbach's alpha coefficient for multi-item scales, ensuring that the items within each scale measured the same underlying construct. A high alpha (>0.7) indicated that the items within each scale were measuring the same underlying construct reliably.

3.5 Data management

3.5.1 Data coding and cleaning

All collected data, was double-entered by two separate individuals so as to minimize errors and facilitate data cleaning in Microsoft Excel sheet from the questionnaires. This involved entering the data into a database twice by different researchers. Following data entry, a thorough examination was conducted to identify any missing data, inconsistencies, and outliers. Frequencies analysis was

conducted to detect for outliers and missing data, decisions regarding their inclusion or exclusion were made based on justification and potential impact on the analysis. Open-ended responses regarding sources of information were coded into a pre-defined coding scheme to facilitate analysis. Codebook documentation was maintained for clarity and consistency.

The obscured information was stored digitally on a secure server with limited entry. Only authorized researchers involved in the study had access to the data. Frequent back-ups were conducted and saved on a separate secure server or cloud storage service to guarantee redundancy in the event of data loss or server failure.

3.5.2 Data analysis

Data obtained from the field was entered into a Microsoft Excel sheet, cleaned, and then exported to IBM Corp, 2017, IBM SPSS statistics for Windows, version 25.0.

Objective 1: Proportions of students with good perception of premarital genotype screening

Respondents' perception was assessed using a 5-point Likert scale ranging from strongly disagree (1) to strongly agree (5). Mean score was computed for each of the variables and graded as 1 = Strongly disagree, 2 = disagree, 3 = neutral, 4 = agree, and 5 = strongly agree. Each positive response to a perception question was awarded a score of one mark while zero mark was awarded to each negative response; the scores were summarized as mean score ranging from 1–5. A score of 1–3 was graded as poor perception whereas scores of 4 and 5 were graded as good perception. Descriptive analysis was used to compute the proportion of students

who have a good perception of pre-marital genotype screening for sickle cell disease who acquired a score of 4 and 5 for good perception. This objective was analysed by calculating the percentage of students who respond affirmatively to inquiries pertaining to perception towards the screening program. The computed percentage indicated the proportion of undergraduate students with a good perception regarding pre-marital genotype screening.

Objective 2: Factors associated with perception of premarital genotype screening.

Bivariate logistic regression was employed to examine the relationship between multiple independent variables and dependent variable (perception) while accounting for possible confounding factors. Adjusted odds ratio, p-values, and 95% confidence interval was used to calculate a statistical significance level of $p<0.05$.

Objective 3: Proportion of students willing to participate in premarital genotype screening.

Descriptive statistics was utilized to ascertain the proportion of students who are inclined to partake in pre-marital genotype screening for sickle cell disease. This was achieved by calculating the percentage of students who select "yes" when asked about their willingness to participate.

3.6 Dissemination of study findings

The results of the study was compiled into a Dissertation that was submitted to the Department of Community Medicine at Kairuki University in partial fulfillment of the requirements for the Degree of Master of Science in Public Health. Copies of the dissertation were also made available at the Kinondoni Municipal Council, the Sickle Cell Unit in Muhimbili National Hospital and Tanzania Commission for Universities.

Moreover, a manuscript has also been prepared and will be submitted to a peer-reviewed open journal for publication.

CHAPTER FOUR

RESULTS

4.1 Enrollment log of study participants

During the study period, a total of 470 undergraduate students at Kairuki University were screened for eligibility criteria and asked to participate in the study via E-mail and text messages using smart phones. Included in the final data analysis was 448 study participants.

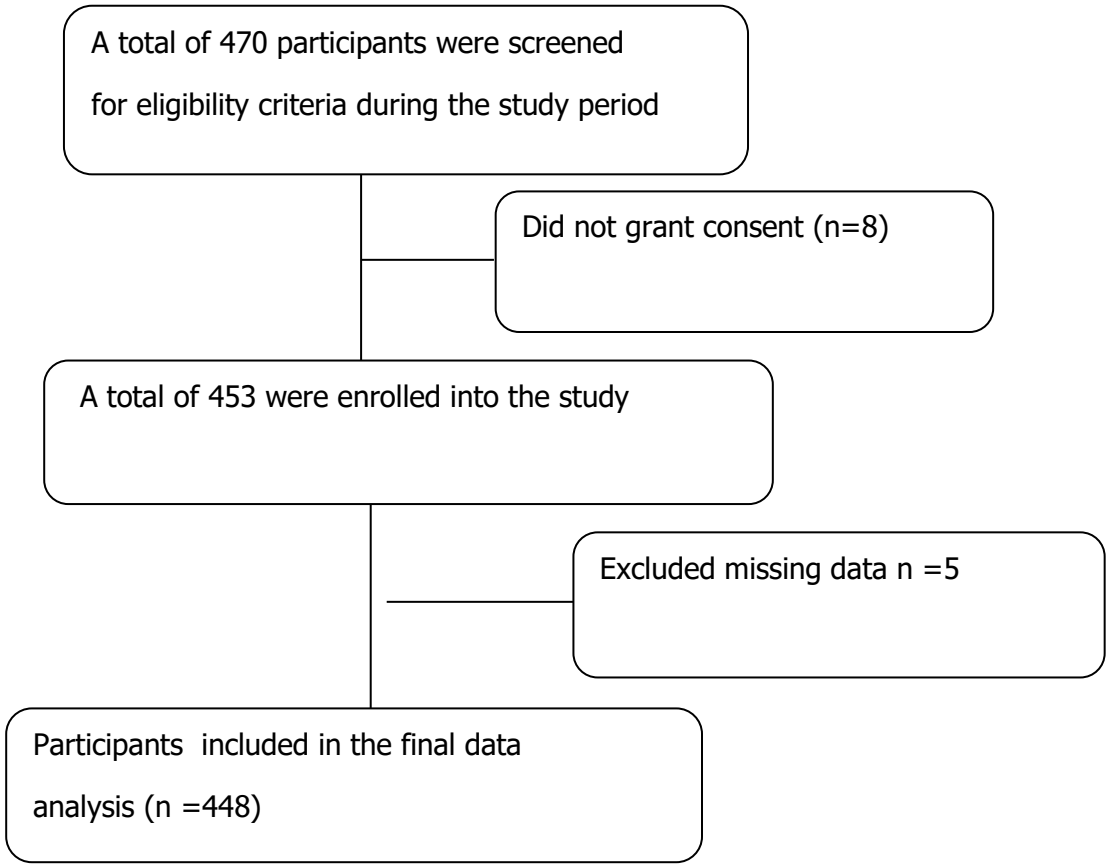

Figure 2: Enrollment flow chart of the study participants

4.2 Socio-demographic characteristics of study participants

Among 488 study participants in the final data analysis there is a diverse range of socio-demographic characteristics. The predominant demographic of the

participants (57.4%) fell within the age group of 18-23 years, accounting for a total of 257 respondents. This suggests a significant prevalence of younger individuals within the context of the study. The analysis of gender composition among the participants underscored a considerable disparity, with females constituting more than half of the respondents (56.5%). A substantial majority of the participants identified as single (95.1%), whereas only 22 individuals (4.9%) reported being married. A significant portion of the participants identified as Christians (68.1%), while 143, representing 31.9%, identified as Muslims. Furthermore, the findings of the study indicated a pronounced concentration of participants enrolled in the Medicine program, comprising 363 individuals (81.0%). This is shown in Table 5 below:

Table 5: Socio-demographic characteristics of the respondents (n=448)

	Variables	**Frequency (%)**
Age in years	18-23	257 (57.4)
	24-29	174 (38.8)
	30-35	17 (3.8)
Gender	Male	195 (43.5)
	Female	253 (56.5)
Religion	Christian	305 (68.1)
	Muslim	143 (31.9)
Marital status	Single	433 (96.7)
	Married	15 (3.3)
Course of study	MD	363 (81.0)
	BScN	60 (13.4)
	BSW	25 (5.6)
Year of study	Year 1	87 (19.4)
	Year 2	98 (21.9)
	Year 3	100 (22.3)
	Year 4	121 (27.0)
	Year 5	42 (9.4)

4.3 Primary outcome - Perceptions of health science undergraduate students regarding premarital genetic screening for Sickle Cell Disease

The study sought to evaluate the perceptions of health sciences undergraduate

students at Kairuki University with regard to premarital genetic screening for SCD. By understanding their views, the study identified gaps in knowledge and areas where misconceptions may exist. This evaluation not only provided insight into the readiness of these future healthcare providers to engage in discussions about SCD with their patients but also highlighted opportunities for targeted educational programs that promote awareness and acceptance of pre-marital genetic screening as a primary prevention intervention to reduce the burden of SCD. In summary, more than half of the total respondents (57.24%) had good perception regarding premarital genetic screening for SCD as shown in figure 5. Majority of the respondents indicated that lectures/ schools (38.5%) and health personnel (22.7%) as the major sources of knowledge of PMGS for SCD. However, 42.76% of the participants had poor perception on PMGS for SCD indicating that a significant number of participants may not perceive PMGS to be a substantial preventive method to reduce SCD burden. This also highlights that a notable portion of respondents might still face or be aware of challenges (e.g., cost, access, or stigma) that could deter participation in screening programs. This is shown in Figure 3 below:

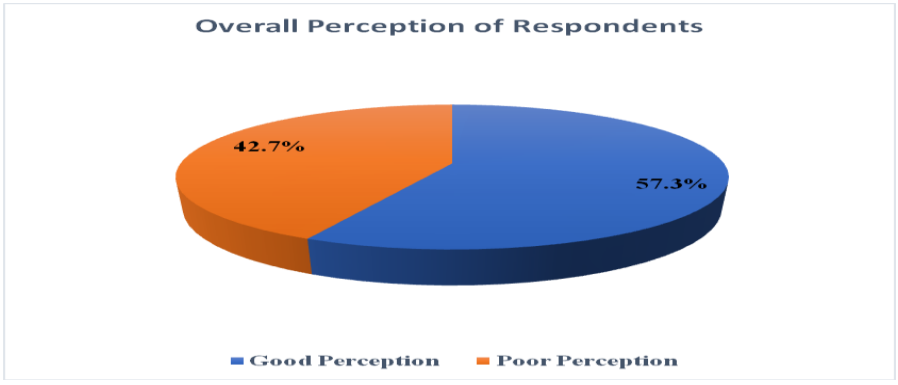

Figure 3: Perception of respondents on premarital genetic screening for SCD

4.4 Factors associated with good perception towards PMGS for SCD

On bivariate and multivariate analysis, the only factor that was found to facilitate good perception is information received from healthcare professionals which had 2.53 times higher odds of having a good perception compared to those who received information from families and friends or media outlets. Other variables such as age, religion, access to healthcare services, information from friends and family, and media show no statistically significant associations with good perception. This analysis suggests that receiving information from healthcare professionals is particularly influential in shaping positive perceptions, whereas other factors may not have a strong effect based on the findings of the study.

This is shown in Tables 6 and 7 below:

Table 6: Bivariate analysis of factors associated with perception about premarital genetic screening for SCD

Variables	Category	Good Perception	Poor Perception	COR	95% CI		p-value
					Lower	Upper	
Age group in years	18-24 25-29 30-35	116 (45.1%) 75 (43.1%) 11 (64.7%)	141 (54.9%) 99 (56.9%) 6 (35.3%)	1.28 Ref	0.8	6.8	0.232
Religion	Christian Muslims	72 (23.6%) 36 (25.2%)	233 (76.4%) 107 (74.8%)	1.09 Ref	0.6	1.7	0.134
Course of study	(BScN) (BSW) (MD)	16 (64.0%) 48 (80.0%) 275 (75.8%)	9 (36.0%) 12 (20.0%) 88 (24.2%)	1.76 Ref	0.7	4.1	0.312
Gender	Male Female	151 (77.4%) 188 (74.3%)	44 (22.6%) 65 (25.7%)	1.19 Ref	0.7	1.84	0.444
Source of information	HCP Media Lecturers Friends	135(92.5%) 24 (85.7%) 80 (92.0%) 95 (81.9%)	11(7.5%) 4 (14.3%) 7 (8.0%) 21 (18.1%)	2.53 Ref	1.0	6.2	***0.042***
Marital status	Single Married	236 (55.4) 10 (45.5%	190 (44.6) 12 (54.5)	1.49 Ref	0.8	2.7	0.231

Key: COR: Crude Odds ratio, CI: Confidence interval, Ref: Reference Category

Table 7: Multivariate analysis of factors associated with perception about premarital genetic screening for SCD

	Variable	Perception about Premarital Screening of Sickle Cell Disease		Univariate analysis		
		Good perception	**Poor perception**	**AOR**	**95% CI Lower-Upper**	**p-value**
Source of information	Media	24 (85.7%)	4 (14.3%)	Ref		
	Friends	95 (81.9%)	21 (18.1%)	0.75	0.41-1.13	0.413
	Lecturers	80 (92.0%)	7 (8.0%)	1.90	1.32-2.66	0.502
	HCP	135 (92.5%)	11 (7.5%)	2.05	1.43-2.92	**0.031**
Course of study	BScN	16 (64.0%)	9 (36.0%)	Ref		
	BSW	48 (80.0%)	12 (20.0%)	2.25	1.60-2.97	0.461
	MD	275 (75.8%)	88 (24.2%)	1.75	1.03-3.09	0.219

Key: AOR-Adjusted Odds Ratio: CI-Confidence Interval: Ref-Reference

HCP – Health care proffessionals

4.5 Participants perceived seriousness of Sickle Cell Disease (Likert Scale)

The findings presented in Figure 4 below show the respondents' perceptions regarding Sickle Cell Disease. While respondents expressed significant concern about the disease's financial strain (81.1%) and its potential to reduce life expectancy (84.2%), which aligns with medical understanding and emphasizes serious health impacts. The fear of SCD due to personal experience was evenly split, the perception of stigmatization associated with having a child with SCD was notably lower (22.3%). This suggested that while respondents were acutely aware of the disease's medical and economic burdens, their concerns about social stigma were less pronounced. Moreover, the impact of SCD on marriage was seen as a serious relational challenge, with over half of respondents (56.3%) agreeing that it could destabilize relationships. These findings illustrated the multifaceted nature of the public's perception of SCD, highlighting both the disease's tangible consequences and the more intangible social and emotional implications.

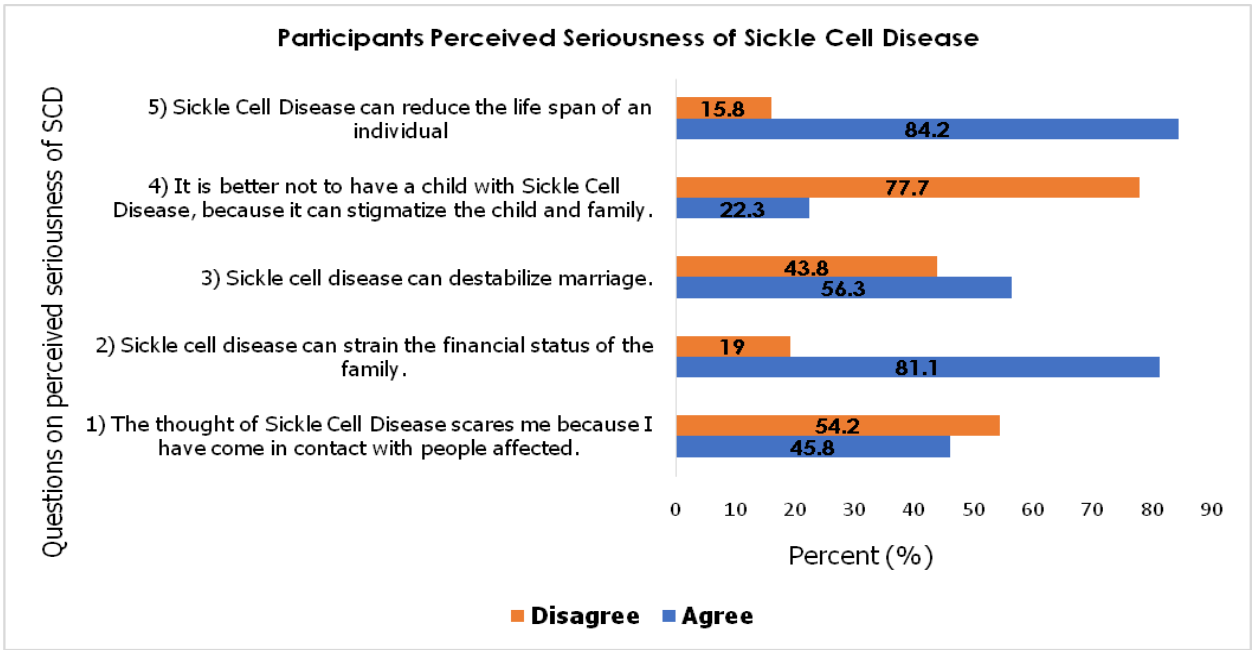

Figure 4: Participants perceived seriousness of Sickle Cell Disease

4.6 Perceived benefits of premarital genotype screening (Likert Scale)

The findings revealed a strong consensus among participants regarding the perceived benefits of premarital genotype screening for Sickle Cell Disease. A significant majority (88.2%) agreed that screening effectively alleviates unnecessary worries about the disease, indicating a positive association between screening and reduced anxiety. Moreover, participants demonstrated a high level of appreciation for the role of genetic screening in determining partner compatibility (82.8%), suggesting that they view it as a valuable tool for understanding genetic risks within relationships. Findings further support that screening is instrumental in making informed choices about marriage, with 71.2% of participants believing it decreases the likelihood of having a child with SCD and 85.0% acknowledging its importance in making informed choices regarding partners with the HbSS trait as shown in Figure 5. These results collectively underscored the strong support for premarital genotype screening and its perceived benefits in reducing concerns about genetic diseases, enhancing compatibility, and facilitating informed decision-making within relationships.

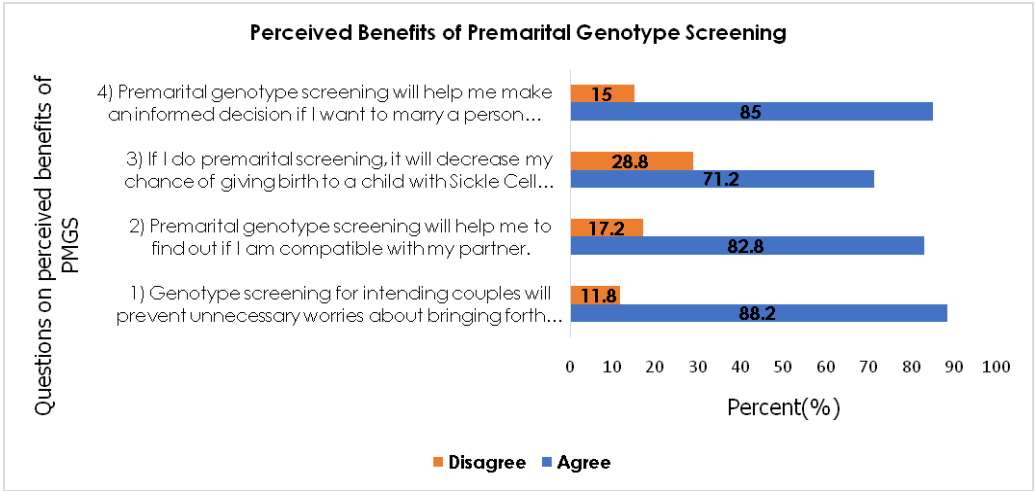

Figure 5: Perceived benefits of premarital genotype screening for SCD

4.7 Participants perceived barriers to premarital genotype screening (Likert Scale)

A significant majority of study participants (71.8%) did not express concerns about premarital screening increasing worries regarding Sickle Cell Disease, while only 28.2% felt this way. Additionally, a very small proportion (11.2%) believed that genotype screening could make them prone to blood-borne diseases, and 11.4% thought the procedure might be painful as shown in Figure 6. These findings demonstrated high confidence in the safety and comfort of the screening process. Furthermore, a substantial majority (77.1%) agreed that the results of their genotype test should be kept private and confidential, indicating a strong desire for privacy and confidentiality. Overall, the data suggested a positive perception towards premarital genotype screening, with low levels of concern regarding its potential negative aspects.

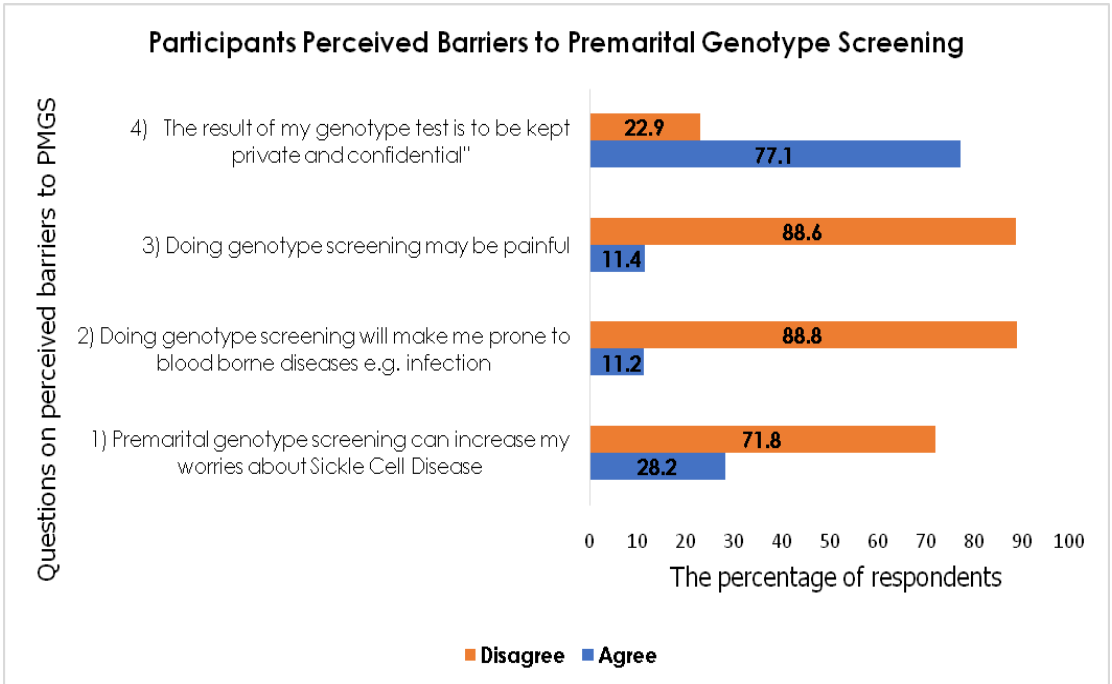

Figure 6: Participants' perceived barriers to premarital genotype screening

4.8 Willingness to participate in premarital genotype screening for SCD

The majority of the respondents (92.2%) indicated that they would opt for premarital genetic screening for sickle cell disease, while only 7.8% of respondents stated they would not opt for the screening.

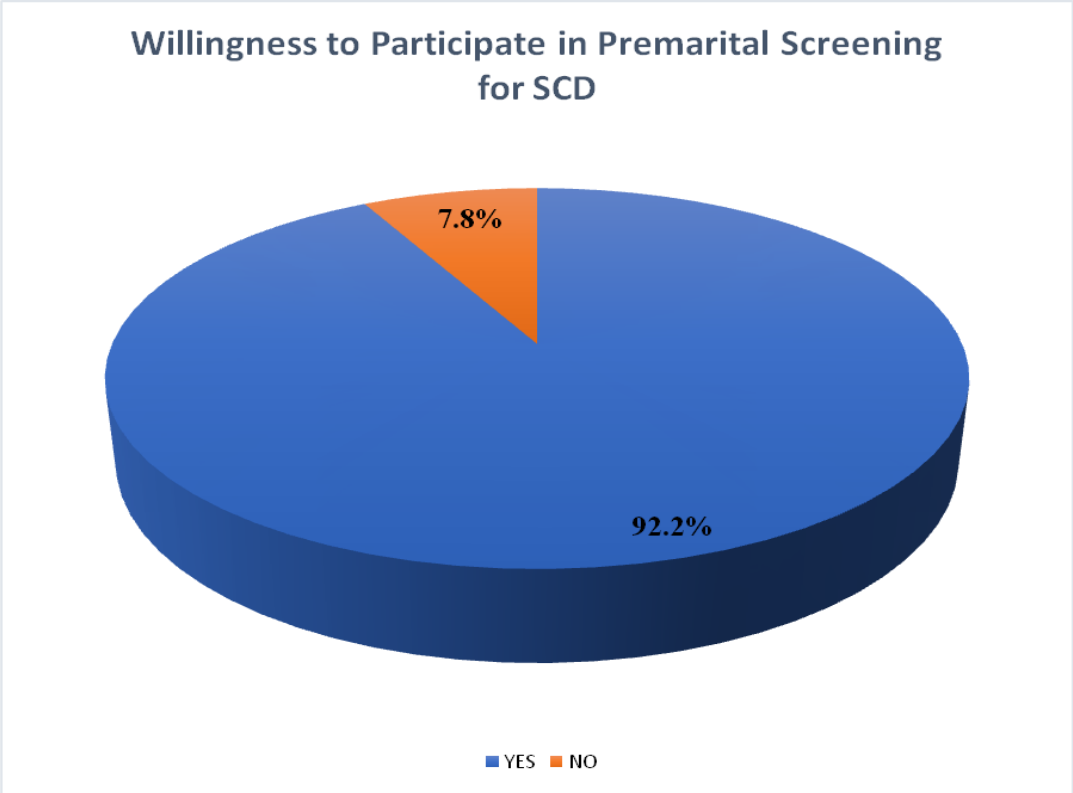

Figure 7: Respondents willingness to participate in premarital genetic screening for SCD

4.9 Willingness to recommend to others for premarital genotype screening for SCD

A substantial number (94.0%) of students expressed a willingness to recommend premarital screening for sickle cell disease to others. This indicates a strong belief in the importance of such screenings for informed family planning and health

management. On the other hand, only 6.0% of respondents indicated that they would not recommend screening to others.

Figure 8: Students willingness to recommend to others premarital genotype screening for SCD

CHAPTER FIVE

DISCUSSION

5.1 Main findings

The study has shown that undergraduate students had good perception on premarital genetic screening for SCD, most students were willing to uptake the genetic screening for SCD and were willing to recommend the screening test to others as well.

5.2 Social-demographic characteristics of the respondents

The findings revealed that most respondents in the study were young adults aged 18-23, comprising 57.4% with the second largest group was aged 24-29, accounting for 38.8%, this is similar to a study done in Khartoum Sudan that reported 59% of the respondents were youth aged 18-25 years (27). The study also indicated that a substantial majority of participants (95.1%), were single, while only 22 participants (4.9%) reported being married. The predominance of single respondents within the sample renders the investigation particularly relevant for the target demographic, as it is imperative for these individuals to comprehend the significance of premarital genotype screening prior to entering matrimony.

The study revealed a notable gender imbalance among participants, with 195 males (43.5%) and 253 females (56.5%). This distribution indicated a predominance of female respondents, which may influence the overall perceptions and willingness to undertake premarital screening for sickle cell disease. This gender disparity could

also suggest that women are more likely to consider premarital screening due to their roles in family planning and childbearing.

5.2 Perceptions of respondents regarding premarital genetic screening for SCD

The study had pointed out that 57.2% of undergraduate students possess a good perception of premarital genetic screening for sickle cell disease, which is very similar to a study conducted in Egypt that indicated a 50.3% rate of positive perception among students (26). The major source of information was found to be lectures (38.5%), followed by health personnel (22.7%), these findings are contrary to those found I Khartoum, Sudan where media was the main source of information (27). These differences show that health personnel are efficient in spreading information on premarital genetic screening, however more effort is required.

In terms of perceived seriousness of SCD, financial constraints was a major worry, with 81.1% agreeing that SCD can adversely affect financial stability, underscoring its economic impact on families, these findings align with a study conducted by Adebamowo et al who found out that financial burden and fear of health implications were significant concerns for families dealing with SCD (33). Additionally, 56.3% of respondents believed that SCD can destabilize marriages, indicating the relational challenges it poses. Interestingly, only 22.3% expressed concern about the stigma associated with having a child with SCD, suggesting less awareness or worry about social perceptions. Conversely, a strong 84.2% agreed that SCD can reduce life expectancy, reflecting serious health concerns.

Regarding perceived benefits of premarital genetic screening for SCD, the findings indicated strong support for genotype screening among participants, with 88.2% agreeing that it helps prevent unnecessary worries about Sickle Cell Disease, these findings aligned with a study by Akinyanju et al in Nigeria, which reported that individuals perceived premarital genotype screening as vital for reducing anxiety related to SCD and improving partner compatibility assessments (34). This suggested that many believe screening reduces anxiety regarding the possibility of having a child with SCD. Furthermore, 82.8% felt that screening helps in assessing compatibility with their partners, while 85.0% agreed that it provides crucial information for decisions about marrying someone with the HbSS trait. These findings were similar to the study done in Ghana which reported that a large proportion of participants believed that premarital genotype screening provides essential information for making informed decisions about marriage and childbearing, reinforcing its perceived benefits in managing SCD risks (32). Overall, participants viewed genotype screening as an essential tool for understanding genetic compatibility and its implications.

In terms of perceived barriers of premarital genetic screening for SCD, the majority (77.1%) agreed that the results of genotype tests should be kept private and confidential, and that lack of privacy would affect their perception towards premarital genetic screening for SCD. This reflected a high value placed on privacy in the screening tests. The concerns regarding privacy and confidentiality surrounding genetic testing are valid and can significantly impact individuals' decisions to engage in premarital genotype screening. The findings from Kassim et al underscored the necessity of prioritizing privacy in discussions about genotype

screening to foster a supportive environment for those considering testing as found in the study findings (35).

5.3 Factors associated with poor perception about premarital screening for SCD

The study found that information from healthcare professionals had higher odds of having a good perception compared to those who received information from friends, family, or media outlets. These finding is contrary to the study conducted in Lagos, Nigeria which revealed that factors, such as the participants' age, educational level, exerted an influence on their level of knowledge concerning sickle cell disease and their perception towards premarital genetic screening for SCD (31). Specifically, as the participants' age and level of education increased, there was a corresponding increase in the number of individuals who possessed a good perception towards premarital genetic screening for SCD (31).

5.4 Willingness to participate in premarital genotype screening for SCD

The majority of respondents (92.2%) expressed willingness to undergo premarital genetic screening for sickle cell disease and (94%) were a willing to recommend premarital screening for sickle cell disease to others. These findings highlighted a strong belief in the importance of such screening for informed family planning and health management and indicated a strong awareness and proactive attitude toward genetic health measures before marriage. These findings align with the findings of a study done in South-West Nigeria among final-year undergraduate students which reported that the majority (92.3%) of the participants were willing to opt for premarital genotype screening for SCD (28). Moreover, a study conducted among

Ugandan University students reported a majority of the students were willing to participate in the premarital screening services and 82.3% agreed that it was important and beneficial and would encourage their partners to screen (4). In contrary, a study done in Sudan reported low willingness (39%) to participate in premarital screening among students, with reasons for low willingness being due to lack of adequate awareness and knowledge in 44.5% on premarital screening programs for sickle cell disease and social and cultural factors in 33% (27).

A study conducted by Adediran et al where a cross-sectional survey design was employed among 500 University students. The results showed that 92% of respondents would recommend premarital screening to others, with high awareness levels about sickle cell disease significantly correlating with their willingness to promote genetic screening for SCD (36).

5.5 Strengths and limitations of the study

5.5.1 Strengths

Firstly, the study targeted health sciences undergraduate students, a specific and relevant group that is likely to have heightened awareness of health-related issues. This allows for a more in-depth examination of perceptions and willingness to undergo premarital screening for sickle cell disease among individuals who may be future healthcare professionals.

Secondly, sickle cell disease is a significant public health issue in many parts of sub-Saharan Africa, including Tanzania. By exploring the factors influencing youths' perception to uptake premarital screening, the findings from the study have the potential to inform and guide health interventions and educational programs

designed to improve early detection and prevention of sickle cell disease, particularly among young people.

Lastly, the study contributed to the understanding of how young adults, particularly health science students, perceive and are willing to engage in premarital sickle cell screening. These findings can be used to inform policy decisions, university health education programs, and wider public health strategies in Tanzania which aim to combat SCD burden.

5.5.2 Limitations

While offering significant contributions to the understanding of determinants of perception and willingness to uptake PMGS for SCD among health sciences undergraduates in KU, it was subject to certain limitations. Firstly, the study focuses on undergraduate students at Kairuki University, which may not be representative of all health sciences students in Tanzania or the broader population of young adults in the country. Health science students may have different perceptions and knowledge about sickle cell disease and the premarital screening tests compared to students in other fields or the general public.

Secondly, the cross-sectional design constrained the capacity to ascertain causal relationships among variables. Consequently, although notable associations were discerned, it could not be conclusively established that these factors directly influenced or impacted health sciences undergraduates' perceptions regarding the uptake of PMGS for SCD. To remediate this limitation, prospective longitudinal investigations could examine the temporal progression of events to enhance causal inferences.

Lastly, the study relied on self-reported data from participants, which can be subject to recall bias. Participants may not accurately report their true perceptions or intentions regarding premarital genetic screening for SCD.

5.6 Conclusions

In summary, over half of the respondents (57.24%) had a good perception of premarital screening for sickle cell disease. This indicates that a considerable number of participants recognize the seriousness of sickle cell disease and value premarital genotype screening as an important tool for making informed decisions about marriage and family planning, particularly in communities where the disease is common. Conversely, 42.76% who disagreed suggest that a significant portion may not perceive significant barriers to screening. However, this also indicates that many respondents might still encounter or be aware of challenges, such as costs, accessibility, or stigma, that could discourage participation in screening programs.
Moreover, healthcare professionals are regarded as more reliable sources of health information than personal contacts or media as individuals who received information from them had good perception towards PMGS for SCD. This highlights that healthcare professionals are efficient in spreading health education and information on PMGS, however more effort is required.

Lastly, a substantial percentage of respondents (92.2%) expressed their intention to undergo premarital genetic screening for sickle cell disease. This indicates a high level of awareness and a willingness to take proactive health measures prior to marriage, demonstrating a favourable attitude toward genetic screening. In addition, a significant proportion of students (94.0%) indicated their willingness to

recommend premarital screening for sickle cell disease to others. This reflects a strong belief in the significance of such screenings for informed family planning and health management. Conversely, only 6.0% of respondents stated that they would not recommend the screening. Thus, health education about sickle cell disease and premarital screening are essential tools to help the youth make informed decisions about their sickle cell status before entering in marriage. This proactive approach can help reduce the SCD burden in the country; by raising awareness through health education, the entire community can enhance its understanding and shift attitudes toward sickle cell disease, leading to greater participation in premarital screening and counselling as a preventive approach.

5.7 Recommendations

5.7.1 Recommendations to Government of Tanzania

a) The Ministry of Health, Community Development, Gender, Elderly and Children in collaboration with the Ministry of Education should develop a curriculum focused on educating the public about premarital genotype screening for sickle cell disease. This education should be delivered through various media channels, schools, health facilities, and public meetings to ensure that everyone in the community can participate in addressing and preventing sickle cell disease.

b) The Ministry of Health, Community Development, Gender, Elderly and Children should establish a policy aimed at encouraging youth in the community to adopt a positive attitude toward undergoing sickle cell screening before marriage. This initiative would help minimize the risk of transmitting sickle cell genetic disorders to future children. Specifically,

individuals with the sickle cell trait (Hb AS) should be encouraged to partner with those who do not carry the sickle cell genotype (Hb AA).

5.7.2 Recommendations to Universities

a) In partnership with the Tanzania Commission for Universities (TCU) and the Ministry of Education, all universities should create age-appropriate curricula on premarital genotype screening for sickle cell disease and counselling, designed for different levels of study. This initiative aims to provide young people with essential knowledge about sickle cell disease from an early age, encouraging them to develop positive attitudes toward premarital screening and to make informed marriage decisions.

b) In all Universities in Tanzania, on-going education about premarital genotype screening for sickle cell disease and counselling should be a crucial aspect for all first-year students. This education should highlight the risks of having children affected by sickle cell disease in our country.

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APPENDICES

APPENDIX 1: CONSENT FORM

Informed Consent Form

Introduction

You are invited to participate in a research study conducted by INDO NDAIGEZE, a Master of Science student in Public Health at Kairuki University (KU). This study being a criterion for partial fulfilment of her degree, aims to understand the perceptions regarding premarital sickle cell disease (SCD) screening of health sciences undergraduate students at KU and their willingness to uptake the screening test.

Purpose of the Study

The information gathered from this study will help us understand:

The student's perception about premarital SCD screening among health sciences undergraduate students.

Factors influencing students' perception about premarital SCD screening.

Students' willingness to participate in premarital SCD screening.

Participation

Your participation in this study is voluntary. You have the right to choose not to participate or to withdraw from the study at any point without penalty.

Procedures

If you agree to participate, you will be asked to complete an anonymous online survey that will take approximately 15-20 minutes. The survey will ask questions

about your demographics, perception of premarital SCD screening, and your willingness to uptake PMS for SCD.

Risks and Benefits. There are no known risks associated with participating in this study. The potential benefits include increased knowledge about premarital SCD screening and SCD itself. The findings from this study may also contribute to the development of educational programs to improve awareness and understanding of SCD screening among healthcare students.

Confidentiality

Your participation in this study will be anonymous. All data will be collected electronically and stored securely. No names or other identifying information will be linked to your responses.

Contacts

If you have any questions about the study, please contact the researcher(s):

INDO NDAIGEZE

indoteddy@gmail.com

+255 769451208

You may also contact the Kairuki University Institutional Research and Ethics Committee (KU-IREC) with any concerns about your rights as a research participant.

Your Consent

By clicking the "I Agree" button below, you are indicating that you have read and understood the information provided in this consent form and that you voluntarily agree to participate in this study.

☐I Agree

☐I Do Not Agree

Thank you for your time and consideration.

Appendix 2: QUESTIONNAIRE

Premarital Sickle Cell Disease Screening Perception Survey

Introduction:

Thank you for participating in this voluntary and anonymous survey. This study aims to understand the perceptions of health sciences students at Kairuki University (KU) regarding premarital sickle cell disease (SCD) screening.

Instructions:

Please read each question carefully and select the answer that best reflects your opinion. There are no right or wrong answers.

Section 1: Demographics

Age: _____ years

Sex:

☒Male

☐ Female

Religion:

☐Christian

☐Muslim

☐Other (please specify): _____

Marital Status:

☐Single

☐Engaged

☐Married

☐Divorced

Course of Study:

☐Medicine (MD)

☐Bachelor of Science in Nursing (BScN)

☐Bachelor of Social Work (BSW)

Year of Study:

☐Year 1

☐Year 2

☐Year 3

☐Year 4

☐Year 5

Section 2: Perception towards Premarital Sickle Cell Disease Screening

2.1 Knowledge of Premarital Screening

Have you ever heard of premarital genetic screening for sickle cell disease?

☐Yes

☐No

2.2 Sources of Information (If yes to question 2.1)

(Check all that apply)

☐Friends

☐Internet

☐Family

☐Media (TV, radio, newspapers)

☐Lectures/schools

☐Health personnel (doctors, nurses)

☐Others (please specify): _____

2.3 Participants Perceived Seriousness of Sickle Cell Disease

Please indicate your level of agreement with the following statements using the Likert scale below:

Statement	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
1) The thought of SCD scares me because I have come in contact with people affected.					
2) Sickle cell can strain the financial status of the family.					
3) Sickle cell can destabilize marriage.					
4) It is better not to have a child with SCD, because it can stigmatize the child and family.					
5) SCD can reduce the life span of an individual					

2.4 Perceived Benefits of Premarital Genotype Screening (Likert Scale)

Please indicate your level of agreement with the following statements using the Likert scale below:

Statement	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
1) Genotype screening for intending couples will prevent unnecessary worries about bringing forth a child with SCD.					
2) Premarital genotype screening will help me to find out if I am compatible with my partner.					
3) If I do premarital screening, it will decrease my chance of giving birth to a child with SCD.					
4) Premarital genotype screening will help me make an informed decision if I want to marry a person that has SS trait.					

2.5 Participants Perceived Barriers to pre-marital genotype screening (Likert Scale)

Please indicate your level of agreement with the following statements regarding barriers to premarital genetic screening test for sickle cell disease using the Likert scale below:

Statement	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
1) Pre-marital genotype screening can increase my worries about SCD					
2) Doing genotype screening will make me prone to blood borne diseases e.g. infection					
3) Doing genotype screening may be painful					
4) The result of my genotype test is to be kept private and confidential					

Section 3: Factors Associated with Perception regarding Premarital Screening (Likert Scale)

Please rate your level of agreement with the following statements regarding factors that may influence your perceptions regarding premarital sickle cell disease screening:

Statement	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
My age group influences my perception of premarital sickle cell disease screening.					
My religious beliefs influence my perception of premarital sickle cell disease screening.					
My access to healthcare services influences my perception of premarital sickle cell disease screening.					
Information from friends and family influences my perception of premarital sickle cell disease screening.					
Information from the media (TV, radio, newspapers) influences my perception of premarital sickle cell disease screening.					
Information from educational lectures/seminars influences my perception of premarital sickle cell disease screening.					
Information from health professionals (doctors, nurses) influences my perception of premarital sickle cell disease screening.					

Section 4: Willingness to Participate in Premarital Screening

Please check all that apply regarding your willingness to participate in premarital sickle cell disease screening:

I would opt for premarital genetic screening for sickle cell disease before marriage.

☐ Yes

☐ No

I would recommend premarital genetic screening for sickle cell disease to others, such as my partner

☐ Yes

☐ No

Thank you for your participation!

Key:

Strongly disagree.

Disagree

Neutral

Agree

Strongly agree.

Indo ndaigeze
P.O.Box 65300
Dar-es-Salaam
4th October 2024.

Director of Postgraduate Studies and Research Institute
Kairuki University
P.O.Box 65300
Dar-es-salaam
U.f.s

Head of department of Community Medicine
Kairuki university
P.O.Box 65300
Dar-es-salaam

Dear Professor,

RE: SUBMISSION OF DISSERTATION FOR MScPH PART II FINAL QUALIFYING EXAM.

Kindly refer to the heading above.

I hereby submit my Master of Science in Public Health dissertation entitled" DETERMINANTS OF PERCEPTION AND WILLINGNESS TO UPTAKE PREMARITAL SCREENING TEST FOR SICKLE CELL DISEASE AMONG HEALTH SCIENCES UNDERGRADUATE STUDENTS, DAR ES SALAAM" as part of MScPH part two Final Qualifying Examination.

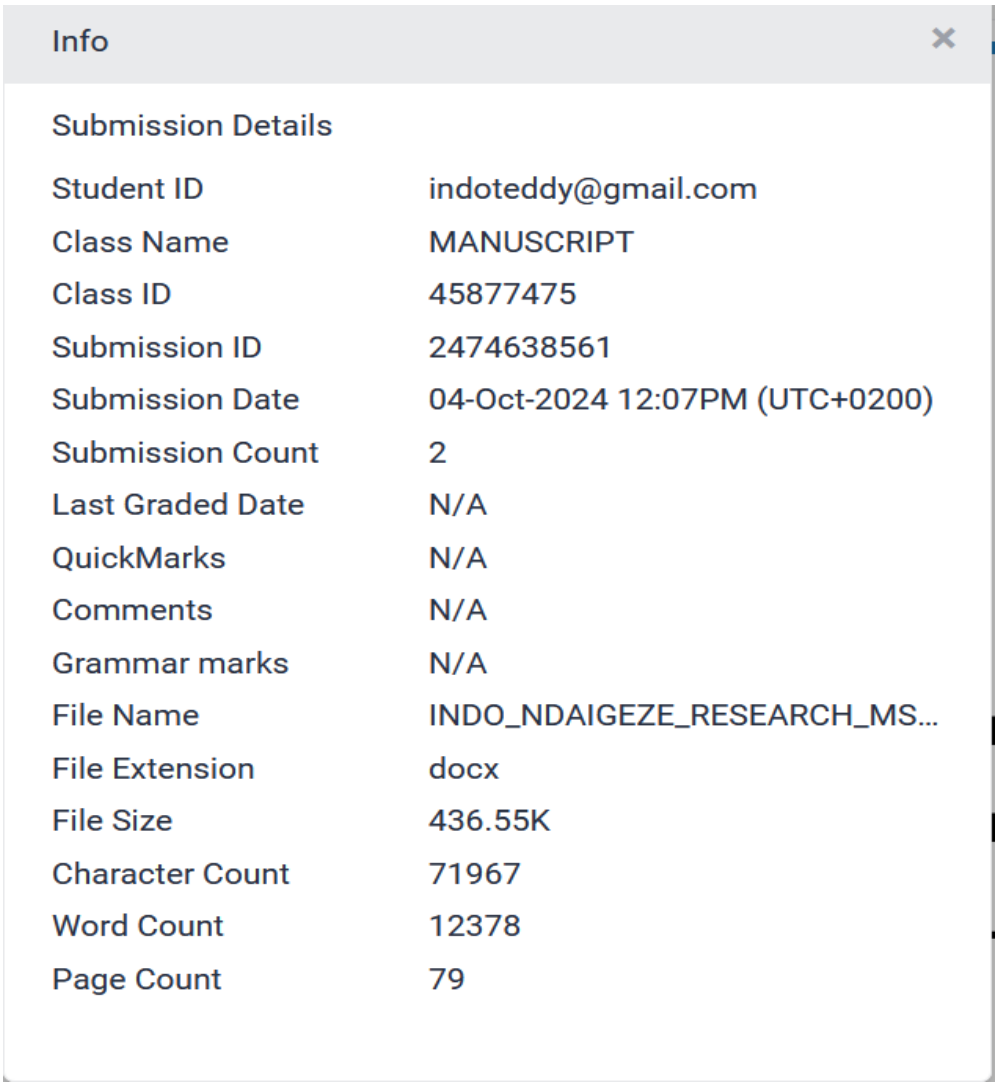
Attached to this letter are two (2) copies of dissertation, and Turnitin (Anti-Plagiarism) report checked in the department.

Sincerely,

…….

Indo Ndaigeze

HK/PG/PH/22/0035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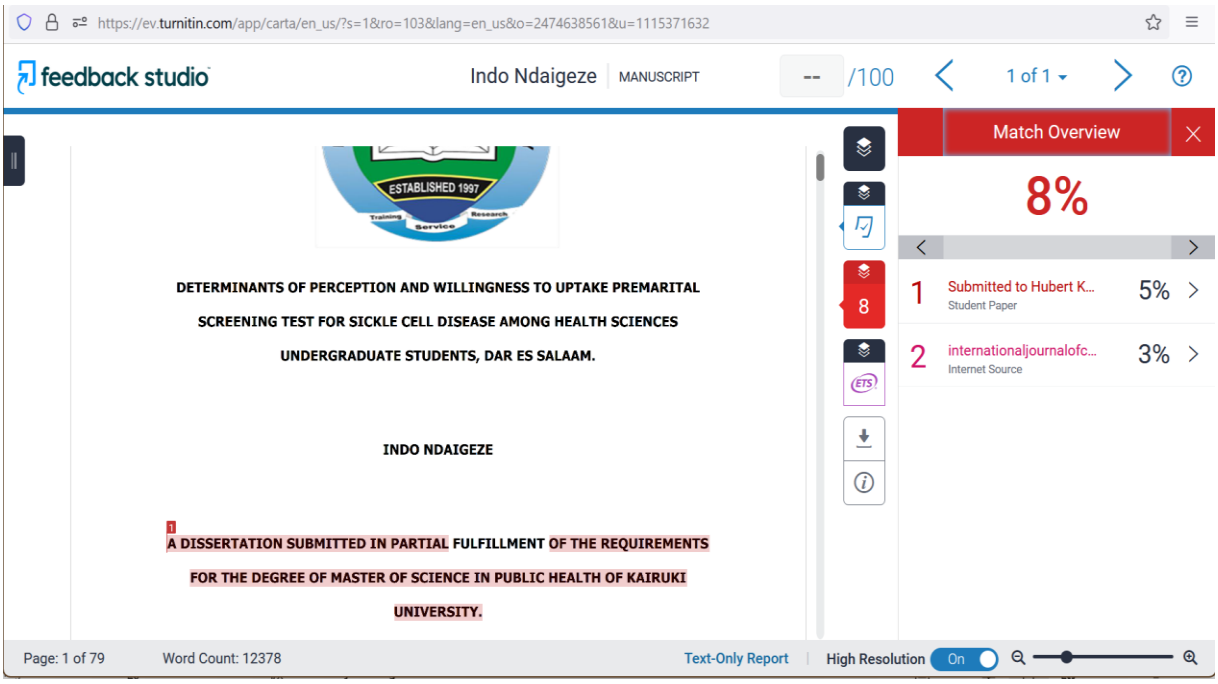
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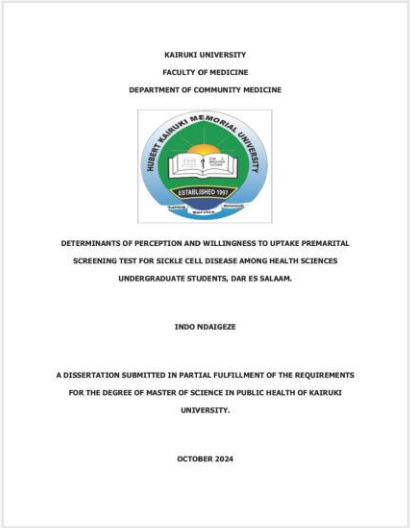

KAIRUKI UNIVERSITY

FACULTY OF MEDICINE

DEPARTMENT OF COMMUNITY MEDICINE

DETERMINANTS OF PERCEPTION AND WILLINGNESS TO UPTAKE PREMARITAL SCREENING TEST FOR SICKLE CELL DISEASE AMONG HEALTH SCIENCES UNDERGRADUATE STUDENTS, DAR ES SALAAM.

INDO NDAIGEZE

A DISSERTATION SUBMITTED IN PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR THE DEGREE OF MASTER OF SCIENCE IN PUBLIC HEALTH OF KAIRUKI UNIVERSITY.

OCTOBER 2024

KAIRUKI UNIVERSITY (KU)

70 Chwaku Street,
Mikocheni,
P.O BOX 65300,
Dar es Salaam,
Tanzania.

Tel: +255-22-2700021/4
Fax: +255-22-2775591
Email: irec@ku.ac.tz
Website: www.ku.ac.tz

Ref. No. KU/IREC/27.10/459 **1st July 2024**

Dr. Indo Ndaigeze,
Kairuki University,
Box 65300,
Dar es Salaam, Tanzania.

RE: ETHICAL CLEARANCE CERTIFICATE FOR CONDUCTING HEALTH RESEARCH.

I am pleased to inform you that the research titled: **Determinants of Perception and Willingness to Uptake Premarital Screening for Sickle Cell Disease Among Undergraduate Students, Dar Es Salaam (Ndaigeze I., 2024)** has been granted ethical approval.

This approval is in effect for one year from the above date. Any changes in the procedures should be reported to the Institutional Research Ethics Committee. Significant changes will require the submission of a revised request for ethical approval. You will be required to submit **study a progress report** every six months.

Permission to publish your findings should be sought from the National Institute for Medical Research (NIMR) before submission to a publisher and not concurrently.

DIRECTOR POSTGRADUATE STUDIES HUBERT KAIRUKI MEMORIAL UNIVERSITY P. O. Box 65300, DSM AND RESEARCH INSTITUTE

CHAIR PERSON
Name: Prof. Fredrick Kaijage
Signature:

SECRETARY
Name: Prof. Columba Mbekenga
Signature:

KAIRUKI UNIVERSITY (KU)

70 Chwaku Street
Regent Estate – Mikocheni
P.O. Box 65300,
Dar es Salaam
Tanzania

Tel: +255-22-2700021/4
Email: secvc@ku.ac.tz
Website: www.ku.ac.tz

INTERNAL MEMO

Date: 10th July 2024.

To: Director of Postgraduate Studies and Research Institute

Re: LETTER OF INTRODUCTION DR. INDO NDAIGEZE (MSCPH – PUBLIC HEALTH)

Kindly refer to your letter dated 9th July 2024 introducing Dr. Indo Ndaigeze for the permission to conduct data collection at Kairuki University with a study titled' "DETERMINANTS OF PERCEPTION AND WILLINGNESS TO UPTAKE PREMARITAL SCREENING TEST FOR SICKLE CELL DISEASE AMONG HEALTH SCIENCES GRADUATE STUDENTS, DAR ES SALAAM".

This is to notify you that the permission has been granted from Kairuki University with an ethics approval No. **KU/IREC/27.10/459** by the KU Institutional Research Ethics Committee

Regards,

Innocent Marandu,
Human Resources and Administration Manager.

KAIRUKI UNIVERSITY
P. O. Box 65300
DAR ES SALAAM

General Contact:
Email: info@ku.ac.tz
Contact: +255 659 371 234

Academic:
Email: dvc-academics@ku.ac.tz
Contact: +255 716 999 151

Admissions:
Email: admissions@ku.ac.tz
Contact: +255 769 724 636
+255 659 371 234