KNOWLEDGE OF SICKLE CELL ANEMIA, ATTITUDE AND PERCEPTION TOWARDS
PREMARITAL GENOTYPE COUNCELLING AND SCREENING AMONG YOUTHS OF
DALA LGA KANO, NIGERIA

BY

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DISSERTATION SUBMITTED TO THE DEPARTMENT OF COMMUNITY MEDICINE,
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AWARD OF BACHELOR OF MEDICINE, BACHELOR OF SURGERY (MBBS) DEGREE.

OCTOBER, 2018.

ATTESTATION

This research work was read and approved by the Department of community medicine, Bayero University, Kano, as having satisfied the requirements for the award of Bachelor of Medicine, Bachelor of Surgery (MBBS) Degree.

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DECLARATION

I hereby declare that this project is a product of my own work, this study is original and my references made at any texts, journal and other persons work have been duly acknowledged by means of references.

SAIDU IDRIS AHMAD (MED/11MBB/00837)

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Signature.....

DATE

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DEDICATION

This project work is dedicated to my parents and all sickle cell disease warriors worldwide.

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First, I would like to thank almighty Allah the most high for guiding me through this great endeavor which I could not have successfully completed without His support.

Secondly, my sincere gratitude goes to my supervisor, Professor Isa Abubakar, who has played a key role both academically and technically in ensuring a high level of quality and standard in this work. I am also grateful to the Head of Department, Community Medicine Professor U.M Lawan for his relentless effort in seeing that well trained students graduate from his department. I also salute my lecturers in Community medicine, especially Prof. M. Kabir, Prof. Zubairu Iliyasu, Prof. Sanusi Dr. Gadanya, Dr. Musa M. Bello and other lecturers in the various departments for their kindness, patience, and love they showed to us throughout our stay in medical school.

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Table of Contents

ATTESTATION.....	ii
DECLARATION.....	iii
DEDICATION.....	iv
ACKNOWLEDGEMENT.....	v
Table of Contents.....	vi
LIST OF TABLES.....	viii
LIST OF FIGURES.....	ix
CHAPTER ONE.....	1
Introduction.....	1
1.1 BACKGROUND.....	1
1.1.1 MODE OF INHERITANCE.....	4
1.2 JUSTIFICATION.....	4
1.3 AIMS AND OBJECTIVES.....	6
CHAPTER TWO.....	7
LITREATURE REVIEW.....	7
2.1 INTRODUCTION.....	7
2.2 HISTORICAL BACKGROUND.....	7
2.3 KNOWLEDGE OF SICKLE CELL ANEMIA.....	9
Nigerian Situation.....	11
2.4 ATTITUDE TOWARDS PREMARITAL COUNSELLING AND SCREENING.....	12
Nigerian situation.....	13
CHAPTER THREE.....	15
3.1 STUDY AREA.....	15
3.2 THE STUDY DESIGN.....	16
3.3 THE STUDY POPULATION.....	16
3.4 SAMPLE SIZE DETERMINATION.....	16
3.5 SAMPLE SELECTION.....	17
3.6 PREPARATION FOR THE STUDY.....	17
3.7 DATA COLLECTION TECHNIQUE.....	17

3.8 DATA ANALYSIS.....	17
3.9 ETHICAL CLEARANCE:.....	17
CHAPTER FOUR.....	18
CHAPTER FIVE.....	35
5.0 DISCUSSIONS.....	35
LIMITATIONS.....	38
CHAPTER SIX.....	39
6.0 CONCLUSION.....	39
6.1 RECOMMENDATIONS.....	39
REFERENCES	40
SAMPLE QUESTIONNAIRE.....	46

LIST OF TABLES

TABLE 1 SOCIODEMOGRAPHIC CHARACTERISTICS

TABLE 2 RESPONDENTS OPINION ON MARRYING A CARRIER

TABLE 3 OVERALL GRADING KNOWLEDGE OF RESPONDENTS

TABLE 4 RELATIONSHIP BETWEEN KNOWLEDGE AND SEX

TABLE 5 RELATIONSHIP BETWEEN KNOWLEDGE AND AGE GROUP

TABLE 6 RELATIONSHIP BETWEEN KNOWLEDGE AND EDUCATIONAL LEVEL

TABLE 7 OVERALL GRADING ATTITUDE OF RESPONDENTS

TABLE 8 RELATIONSHIP BETWEEN ATTITUDE AND SEX

TABLE 9 RELATIONSHIP BETWEEN ATTITUDE AND EDUCATIONAL LEVEL

LIST OF FIGURES

Fig 1.1 Gender distribution of respondents

Fig 1.2 Marital status

Fig1.3 Religious distribution

Fig 1.4 Tribal distribution of respondent

Fig 1.5 Occupational distribution of respondent

Fig 1.6 Level of education

Fig 2.1 Distribution of respondents that have/not heard of sickle cell disease

Fig 2.2 Respondents understanding of sickle cell disease

Fig 2.3 Respondents knowledge of mode of acquisition of sickle cell disease

Fig 2.4 Respondents have heard of sickle cell carrier

Fig 2.5 Respondents' knowledge of sickle cell carrier

Fig 2.6 Respondents knowledge of complication of sickle cell disease

Fig 2.7 Respondent knowledge about cure

Fig 2.8 Respondents knowledge on mode of treatment

Fig 3.1 Respondents knowledge on premarital genotype counseling

Fig 3.2 respondent opinion on premarital genotype counseling

Fig 3.3 Respondent distribution of those that know their genotype

Fig 3.4 Respondent knowledge of partners genotype ABSTRACT

ABSTRACT

BACKGROUND: The study (descriptive cross sectional) was carried out between April. 2018 to Oct. 2018 in order to assess the knowledge of sickle cell anemia, attitude and perception towards premarital genotype counseling and screening among 190 youths of Dala LGA of Kano.

METHOD: A pre-tested, structured self-administered questionnaire was distributed to the respondents in their respective houses and schools. The sample were selected using simple random sampling.

RESULT: The study revealed that only 28.9% had good knowledge about Sickle cell disease (SCD). However, only 33% and 31% of the respondents knew their haemoglobin genotype and that of their serious fiancés respectively. Respondents' gender appeared to have a significant influence on their knowledge ($P<0.05$) with males having relatively better knowledge than female.

CONCLUSION: There is a significantly deficient knowledge and perception about sickle cell disease among youths in Kano especially concerning the concept of the disease, mode of transmission and prevention. Increase in public awareness about the disease more especially among students in secondary and tertiary institutions as well as provision of free genetic screening, premarital counseling and testing, counseling and health education of the affected individuals need to be emphasized. In addition, government should regard the disease as an important public health burden and it should come up with national SCD control strategies that will aim at reducing the disease to the barest minimum

CHAPTER ONE

Introduction

1.1 BACKGROUND

Sickle cell disease (SCD) is a hereditary disorder in which an individual has inherited two abnormal Hb genes, at least one of which is responsible for the production of sickle Hb (HbS).⁽¹⁾ Whereas sickle cell anemia is characterized by inheritance of two abnormal HbS genes, giving rise to HbSS. The most common clinical phenotype is the homozygous, i.e. HbSS, also known as sickle cell anaemia. Compound heterozygous include HbSC, SD, SO-Arab and Sbthal, which are all collectively (in addition to SS) referred to as SCD.⁽¹⁾

Genetic counseling has been defined as "the process by which patients or relatives at risk of a disorder that may be hereditary are advised of the consequences of the disorder, the probability of developing or transmitting it and the ways this may be prevented, avoided or ameliorated⁽²⁾. Premarital genotype screening presents an opportunity for individuals to become informed about their genetic predisposition to diseases and for couples to be aware of the possible genetic characteristics of their unborn children. Hence, if one holds the view that one of the reasons for marriage is procreation, then worrying about genetic compatibility and avoiding genetic inheritance of grave consequence becomes something to strongly consider⁽³⁾. A policy of detecting carriers and informing them of their risk, and possibilities for reducing it, usually leads to a fall in births and deaths of affected children.⁽⁴⁾

Sickle cell disease (SCD) is one of the commonest monogenetic diseases worldwide. Its greatest burden lies mainly in Sub-Saharan Africa, Mediterranean regions, Middle East and South-East Asia. In Nigeria, about 20 to 30% of the population are carriers of the sickle cell trait.

Sickle cell disease affects about 2 to 3% of the Nigerian population.⁽⁵⁾ The prevalence of sickle cell trait ranges between 10 and 45% in various parts of sub-Saharan Africa . In Nigeria, carrier prevalence is about 20 to 30%. SCD affects about 2 to 3% of the Nigerian population of more than 160million. In people heterozygous for HbS, the polymerization problems are minor, because the normal allele is able to produce over 50% of the haemoglobin.⁽²⁾ Carriers have symptoms only if they are deprived of oxygen or while severely dehydrated.

The most common features of SCD are chronic haemolytic anaemia and recurrent vaso-occlusion. The latter is responsible for the painful crises that characterise the disease. There is also a chronic vasculopathy triggered by free heme resulting in nitric oxide scavenging and upregulation of adhesion molecules in reticulocytes, neutrophils and endothelial cells. This is further complicated by a procoagulant state following the activation of platelets. There is smooth muscle dystonia and eventual hyperplasia, which contributes to vascular occlusions. This explains the plethora of features and complications seen in SCD⁽¹⁾

Pain associated with vaso-occlusive crises is due to microvascular occlusions triggering the activation of nociceptive afferent nerve fibers. Children younger than 3 years are prone to painful swelling of the hands, known as hand-foot syndrome or dactylitis. Long bones and joints are often areas of necrosis leading to pain. Micro vaso-occlusion in the mesenteric blood vessels also causes intense abdominal pain . In 2003, Komba and colleagues⁽⁶⁾ published findings from a study of 236 SCD children (age 8 months–2 years) in Benin, and reported that that 77.5% experienced painful vaso-occlusive crises, with an average of 3.3 episodes per patient.⁽⁶⁾

Sickle cell patients may be shorter or smaller than normal at their childhood. Puberty is often delayed but considerable growth takes place in late adolescence adults with sickle cell anemia are at least as tall as normal. Adult patients with severe anemia, who suffered vertebral

infarction and collapse may be shorter than normal. Another Physical effect of SCD is that the abnormal faces results from extension of the marrow into the cortical bone causing widening of the diploe spaces and thinning of the bone cortex. Bone Pain Crisis (BPC) is another common complication associated with SCD that usually affect the long bones such as femur and humerus, vertebrae, pelvis, ribs and sternum. High risk of infections were linked to impaired splenic synthesis of immunoglobulins as a result of loss of splenic function with about 30% occurs by first year of life and 90% by sixth year of life⁽⁷⁾

In HbSS, the full blood count (FBC) reveals haemoglobin levels in the range of 6-8g/dl with a high reticulocyte count. In other forms of sickle cell disease, Hb levels tend to be higher. A blood film may show features of hyposplenism (target cells and Howell-Jolly bodies). Sickling of the red blood cells, on a blood film, can be induced by the addition of sodium metabisulfite. The presence of sickle haemoglobin can also be demonstrated with the "sickle solubility test". A mixture of haemoglobins (HbS) in a reducing solution (such as sodium dithionite) gives a turbid appearance, whereas normal Hb gives a clear solution. Abnormal haemoglobin form can be detected on haemoglobin electrophoresis, a form of gel electrophoresis on which the various types of haemoglobin move at varying speed. HbSS and HbSC can be identified here. The diagnosis can be confirmed with high –performance liquid chromatography (HPLC). Genetic testing is rarely performed, as other investigations are highly specific for HbS and HbC. An acute sickle cell crisis is often precipitated by infection. Therefore, a urinalysis to detect an occult UTI to look for occult pneumoniae should be routinely performed.⁽⁸⁾

Many of the manifestations of sickle cell disease can be better managed if the diagnosis is made early and regular prospective follow up instituted. The management of sickle cell anaemia is in two phases quiescent stage and crisis stage.⁽⁸⁾ In the quiescent stage, the hall mark attaining

a relatively steady state of health via lifestyle, malaria prophylaxis, folic acid supplementation, vaccination etc. Whilst in the crisis stage, the aim is resuscitating the patient and treating the culprit trigger.

1.1.1 MODE OF INHERITANCE

Sickle cell anaemia are inherited from parent the same way as blood type, hair colour and texture, eye colour and other physical traits. The type of haemoglobin a person makes in the red blood cells depend upon what haemoglobin genes are inherited from his parents.

1. If one parent has sickle cell anaemia (SS) and the other has sickle cell trait (AS), there is a 50% chance of a child's having sickle cell disease (SS) and a 50% chance of a child's having sickle cell trait (AS).

2. When both parents have sickle cell trait (AS), they have a 25% chance of a child's having sickle cell disease(SS).⁽⁸⁾

1.2 JUSTIFICATION

Despite a long history of knowing the genetic cause of sickle cell disease (SCD), progress in developing treatments to prevent painful vaso-occlusive crises and the other myriad of associated symptoms has, until recently, been disappointingly slow.⁽⁹⁾ Sickle cell disorder, understandably, concerns millions of Africans. In Nigeria, there is no doubt that the prevalence of the condition is increasing, especially among the urban educated elite and in other communities with access to effective basic health care. There is however, a palpable lack of information and education about the disorder within our communities. This, with the increasing prevalence, has encouraged the growth of myths, misinformation, inappropriate treatment,

frustration and stigmatisation. The frustration has kindled the desire in many Africans to *do something about sickle cell disorder*. What needs to be done often appears to be deceptively easy and it is usually not fully thought out and remains a subject of confusion and of controversy even among doctors and other health care workers. In this regard, one frequently hears talk of eradication of the disorder by enactment of legislation while the wider context of control is invariably overlooked.⁽¹⁰⁾

Nigeria accounts for 50% of sickle cell disease (SCD) births worldwide and about 2.3% of her population suffers from SCD with 25% of Nigerians being healthy carriers⁽²⁾ Currently, in Nigeria and other West African states, treatment and control of SCD are largely suboptimal. Improved knowledge regarding SCD phenotypes and its comprehensive care among Nigerian physicians will enhance quality of care for affected persons⁽¹¹⁾ Despite the high burden of SCD in Nigeria, a national policy to combat the disease is still awaiting ratification and many of the new modalities of management are not widely available. In 2010, the Nigerian SCD Network (NSCDN) was established as a cooperating body bringing together Nigerian physicians, nongovernmental organizations (NGOs) and other interested bodies both within the country and in the Diaspora.⁽¹⁾

Most studies conducted regarding sickle cell disease in Nigeria focused on the contemporary management of sickle cell disease. In northwestern Nigeria where the sickle cell statistics are most disturbing, there is need for more studies regarding the knowledge of sickle cell disease and various preventive strategies, one of which is premarital counseling. This study aims to address this, by assessing the knowledge of sickle cell anemia and attitude towards premarital counseling amongst students of Bayero university kano. This will give a clue as far

the control measures need to be taken by the policy makers to alleviate this menace of sickle cell disease.

1.3 AIMS AND OBJECTIVES

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GENERAL OBJECTIVES

To assess the knowledge, of sickle cell anemia attitude and perception towards premarital genotype counseling and screening among youths in Dala local government Kano

SPECIFIC OBJECTIVES

1. To determine respondents knowledge of sickle cell anemia and premarital genotype counseling and screening among youths in Dala local government Kano
2. To identify the respondents' perception about sickle cell anemia and premarital genotype counseling and screening
3. To identify the respondents' attitude towards sickle cell anemia and premarital genotype counseling and screening.

CHAPTER TWO

LITREATURE REVIEW

2.1 INTRODUCTION

This chapter contains a review of some available literature regarding knowledge of sickle cell anemia, perception and attitude of people towards premarital counseling of sickle cell anemia. The literature information was obtained from local and international journals, World Health Organization publications as well as the websites on the internet. Internet websites studied and reviewed include: Pubmed, Google and Google scholar.

2.2 HISTORICAL BACKGROUND

Historians believe that DNA mutations, which were responsible for the first versions of the sickle cell gene, originally arose in various African regions including Cameroon, Central Africa Republic. Studies show that the Trans-Atlantic slave trade introduced the sickle cell gene into the Americas and the Caribbean islands. African slaves, who carried the sickle cell trait, had the specific β -globin gene. Studies have shown that, carriers who had the sickle cell trait, had a heterozygote advantage of being resistant to malarial infection. The Indo-European sickle mutation also originated in the Indus Valley Harappa. This particular mutation is found in Saudi Arabia, Oman, Bahrain, and Kuwait.⁽¹²⁾

This collection of clinical findings was unknown until the explanation of the sickle cells in 1904 by the Chicago cardiologist and a professor of medicine k James B. Herrick (1861 - 1954),⁽⁸⁾ whose intern Ernest Edward Irons (1877 -1959),⁽⁸⁾ found "peculiar elongated and sickle - shaped" cells in the blood of Walter Clement Noel, a 20 - year – old first year dental student from Canada after Noel was admitted to the Chicago Presbyterian Hospital in December 1904

suffering from anaemia. Noel was readmitted several times over the next three years for "Muscular rheumatism" and "bilious attack". Noel completed his studies and returned to the capital of Grenada to practice dentistry. He died of pneumonia in 1906 and is buried in the catholic cemetery as Sauteurs in the north of Grenada.⁽⁸⁾

The disease was named "Sickle cell anaemia" by Vernon Mason⁽⁸⁾ in 1922. However, some elements of the disease have been recognized earlier: A paper in the southern journal of medical pharmacology in 1846 described the absence of a spleen' in the autopsy of a runaway slave. The African medical literature reported this condition in the 1870s, where it was known locally as ogbanjes ("Children who come and go") because of the very high infant mortality rate caused by this condition. A history of the condition tracked reports back to 1670 in one Ghanian family⁽⁸⁾

A British colonial medical officer, E. A. Beet,⁽¹²⁾ stationed in Zimbabwe in the 1940s, first observed that blood from malaria patients, who carried the sickle cell trait, had fewer malarial parasites compared to blood from patients without the trait. However, in the 1950s, Anthony C. Allison⁽¹²⁾ developed his own hypothesis on the association of malaria and the sickle cell trait. By following up on Beet and a physician in Zaire during that time, Allison was able to hypothesize that the sickle cell trait offered protection against malaria. He believed that people with the sickle cell trait did not easily succumb to malaria as often as people without the trait. Some evidence against Allison's hypothesis shows no difference in the concentration of blood-borne malarial parasites that exist in people with the sickle cell trait compared those without it. However, research shows that the sickle cell traits offer more protection against malaria to children than to adults, and adults are able to develop antibodies that can attack parasites in the immune system and increase their survival rate in malarial climates. Compared with adults, young children are not able to produce antibodies to the malaria disease until their immune system is more mature (Bloom, 1995).⁽¹²⁾

2.3 KNOWLEDGE OF SICKLE CELL ANEMIA

Over the past decades, several studies have been conducted about sickle cell disease. However results showed that there is still substantial lack of knowledge concerning mode of inheritance of SCD, participants own genotype, symptoms of SCD and various treatment strategies for SCD.

In a study conducted in Gujarat, India involving patients with positive sickle cell status has shown that, out of total 276 cases of which 264 (96%) had Sickle Cell Trait, while 12 (4%) had Sickle Cell Disease. Only 9 % of participants knew that Sickle Cell Anaemia is a hereditary disease. Out of 174 females, only 11 of them knew that SCA is a hereditary disease. While, out of 102 male participants 14 knew about hereditary nature of SCA.⁽¹³⁾

Another study conducted in Missouri USA showed there is inadequate knowledge of SCA among African-American women. Regarding genetics of SCD, Many women understood that SCD is an inherited disorder but had limited knowledge about the inheritance pattern of SCD. Ninety-one percent of women agreed that an individual is born with SCD; however, 6% believed one could get it from a blood transfusion or another manner. Less than 10% of the women surveyed understood the inheritance pattern of SCD; most believed that SCD skips generations. The majority of the women surveyed (52%) were unaware of the different types of SCD. Only 36% (58/162) and 12% (20/162) were aware of C-trait and 1-thalassemia trait, respectively. Within this group, even fewer women were aware of their personal trait status. Most women (90%) believed that they knew their sickle cell trait status, 27% knew their C trait status, and only 10% knew their 3-thalassemia trait status. Concerning knowledge about treatment strategies, only 44% understood that blood transfusions were an important therapy for treating SCD. Eighty-six percent believed that no cure is available for SCD, failing to recognize that

human-leukocyte-antigen (HLA)-matched sibling stem cell transplant can offer a cure for SCD.

(14)

A study was conducted to evaluate the general knowledge of SCD among 334 students from a university in southeastern Texas. Study results illustrated that approximately 81% of students were not unaware of the genotype describing SCD, and more than 60% of students were unaware that SCD is a preventable disease if individuals made “responsible” reproductive decisions. On the other hand, 63% of students were able to correctly answer knowledge questions regarding symptoms of SCD.⁽¹²⁾

In another study done in East Bay Northern California it was found out that; Seventy percent (n= 197) of respondents endorsed that SCT causes health problems. Thirty-one percent incorrectly believed that SCT can turn into SCD. The majority of respondents knew the genetic significance of trait, with 81.6% (n=230) correctly responding "if you have SCT, you can have a child with SCD," and 78% (n = 220) correctly responding that "your child with SCT might have a child with SCD in the future."⁽¹⁵⁾

In a recent study carried out in Western Sudan it was found out that about 46.9% (175) of the respondents had poor knowledge, 26.1% had satisfactory knowledge and 26.9% had good knowledge of SCD. About 68.5% of the respondents indicated that sickle cell disease was an inherited disorder, and 79.9% believed that both mothers and fathers contribute to disease transmission to offspring. About 69.5% agreed that marriage to a close relative might increase the risk of having a child with the disease, whereas only 31.3% agreed that it was useful to know that he or she was a carrier or the partner was carrier of SCD.⁽¹⁶⁾

In a research conducted in Sekondi-Takoradi metropolis in Ghana has showed that out of a total of 621 individuals recruited, 52.5% (326) had knowledge of their hemoglobin (Hb)

electrophoretic pattern while 47.5% (295) had none. In addition, 93.4% individuals had knowledge of SCD while 6.6% had no knowledge of SCD. Older individuals exhibited better knowledge of their Hb electrophoretic pattern than the younger ones ($P = 0.019$). Individuals with tertiary education and married couples exhibited higher knowledge of SCD when compared to their counterparts ($P < 0.001$).⁽¹⁷⁾

Nigerian Situation

A research was carried out in 2015 involving 329 undergraduate students of Ebonyi State University, Ebonyi southern Nigeria, showed the following result; all the participants (100%) were aware of the existence of SCD. Lectures were the most frequent source of information, 115 (35%). Other sources of information include health workers 63 (19.1%), friends and colleagues 55 (16.7%), family members 37 (11.2%), radio and television 34 (10.3%), Library 11 (3.3%), internet 5 (1.5%) and posters 1 (0.3%). One hundred and ninety one (58.1%) of the participants have adequate knowledge about SCD. Three hundred and seventeen (96.4%) participants know that SCD is an inherited disease; 309 (93.9%) know that SCD affects the red blood cell and can be diagnosed with blood test; 34(10.3%) believe that SCD is contagious; Only 97 (29.4%) know the features that are commonly associated with SCD; 242 (73.4%) know that SCD can be detected by haemoglobin genotype; 306 (93%) know that sickle cell disease can be prevented and 153 (46.5%) know the ways through which SCD can be prevented. Some of the participants also showed misconceptions about SCD, example SCD is caused by witchcraft, evil spirit, curse by enemies and punishment from God.⁽¹⁸⁾

Another research published in Annals of postgraduate medicine Ibadan 2015, involving 370 youth corps members serving in Benin city showed that; Only 17.8% of the respondents had a good knowledge of SCD despite high level of awareness (98.4%). Those who studied courses

related to medical sciences had significantly higher mean knowledge score. About 94.6% of the respondents knew their SCD carrier status⁽⁵⁾.

In a study involving 320 Local government workers from Ile-Ife, it was found out that majority (69%) of the study subjects had poor knowledge of SCD, while only (31%) had good knowledge of sickle cell disease. ⁽¹⁹⁾

In Jos metropolis, Plateau state a study involving 137 secondary school students was conducted. The following result was obtained, Majority (83.2%) of the respondents were aware of SCDs, as an inherited disorder (80.0%), affecting the red blood cells (83.0%) but only half (54%) knew that the disease can only be diagnosed through blood test. Also, only 59% knew their genotype and 11.1% claimed AS genotype. More than one fourth (25.5%) had wrong belief that SCD is caused by evil spirit⁽²⁰⁾.

2.4 ATTITUDE TOWARDS PREMARITAL COUNSELLING AND SCREENING.

A cross-sectional study conducted at the students' clinic in Oman from January to April 2011. A self-administered questionnaire was distributed to 590 unmarried Omani students of both genders. The vast majority of the participants (n=540;92%) thought it is important to carry out premarital screening of sickle cell disease and agreed to do it. Around half of the participants (n=313; 53%) favored having premarital screening as an obligatory procedure before marriage and about one third (n=212; 36%) favored making laws and regulation to prevent marriage in case of positive results. ⁽²¹⁾

A study was performed to assess the acceptance of premarital health counseling including sickle cell screening, involving 13 Primary Health Care centers in Riyadh Saudi Arabia. The study indicated that 364 (75.2%) of the study population accepted the concept of Premarital Health Counseling. PMHC was positively affected by the advancing age, experience of marriage,

educational level and well-understood Islamic health related issues. Out of those who accepted the concept, 273 (75%) agreed on the exchange of PMHC certificates between couples to be married and 152 (42%) agreed on the implementation of legislation on PMHC. Also, 298 (82%) of them wanted PMHC to be confidential and 168 (46%) agreed to the concept despite its cost. As regards the location of PMHC, most of participants who agreed to PMHC would prefer it to be given at governmental establishments.⁽²²⁾

A community-based, descriptive, cross-sectional study was conducted in three towns in western kordofan state, Sudan. It was found out that; 48.0% had a satisfactory attitude towards sickle cell disease, 30.7% had a poor attitude and 21.3% showed a good attitudes towards the disease. About 73.1% agreed that conducting sickle cell testing of all family members is important and 52.5% stated that they would not have gotten married to a partner if they knew they were both carriers and may have children with the disease.⁽¹⁶⁾

Nigerian situation

Descriptive cross-sectional study was carried out between September and November 2015 at Ebonyi State University, which is located in Abakaliki, Ebonyi State, South-eastern Nigeria. Out of total of 329 participants studied three hundred and nineteen (97%) participants accepted to go for premarital genetic counseling and 316 (96%) accepted that it is important for people to go for premarital genetic counseling and be screened for haemoglobin genotype. Three hundred and twenty (97.1%) accepted that it is good to know partner's genotype before marriage while 246 (74.8%) did not accept to continue with the marriage if there is risk of sickle cell disease in the offspring.⁽¹⁸⁾

A cross-sectional descriptive study of all members of staff in two randomly selected local government areas (LGAs) in Ile-Ife on knowledge and attitude towards premarital screening was

carried out. In this study, the majority of the 300 respondents (86.7%) and their partners (74.0%) have had sickle cell screening, and there is a favorable attitude towards screening in 95% of the respondents. while 23 (26.1%) of the 88 respondents engaged to a marital partner (committed to a marital relationship) did not know their future partner's sickle cell status. Among those who knew both their sickle cell status and that of their partner (Table 7), high proportions (34.4–64.5%) of subjects with haemoglobinopathy stated that they will continue with conjugal relationships. Even when both partners have haemoglobinopathy, as many as 50% did not decide to discontinue the relationship.⁽¹⁹⁾

Another study carried out at General out Patient Clinic of Nnamdi Azikiwe University Teaching Hospital involving premarital couples with sickle cell disease showed that; An equal percentage of males ($\chi^2 = 24.704$; $df = 6$; $P = 0.000$) and females ($\chi^2 = 12.684$; $df = 6$; $P = 0.048$) (67.9% or 144/212) would call-off their marriage if there was risk of their offspring being HbSS.

(23)

CHAPTER THREE

METHODOLOGY

The study assessed the level knowledge of sickle cell anemia, attitude and perception towards premarital genotype counseling and screening among youths of Dala L.G Area in Kano, Northern Nigeria.

3.1 STUDY AREA

The study is to be carried out in Dala Local Government Area in Kano State, Nigeria. Kano State is a state located in Northern Nigeria. Created on May 27, 1967 from part of the Northern Region, Kano state borders are Katsina State to the North-west, Jigawa State to the North-east, Bauchi State to the South-east and Kaduna State to the South-west. The state originally included Jigawa State which was made a separate state in 1991. The official language of Kano State is Hausa language, but Fulani language is also spoken. Kano State has a population of 9,401,288 according to 2006 National Population Census, officially making it the most populated state in the country. The state is mostly populated by Hausa people. More than 95% of the people of Kano are Muslims, and as such Islam influences personal and community affairs and decisions. Kano is regarded to as Center for Commerce and some of the people there engage in farming. Majority of the women in Kano are rarely seen on the farmlands, offices, markets, and mosques both in urban and rural areas of the state doing business or working rather they could be seen attending formal and informal schools including universities¹. It is also the largest industrial center in the North and second to Lagos in the country. It is also an area for tourism and culture. There are 44 Local governments in Kano State Dala inclusive.

Dala is a densely populated area which was created in May, 1989 from the old Kano Municipal Local Government. It has 12 wards and is located in the North-west part of the Kano metropolis. It has geographical coordinates of 12°01'N 8°29'E and an area of 19 km² and it has a population of 493,880 in 2011 projected by National Population Commission of Nigeria.

3.2 THE STUDY DESIGN

Descriptive cross-sectional study

3.3 THE STUDY POPULATION

The study population comprised of the youths within the age range of 15-24 years.

3.4 SAMPLE SIZE DETERMINATION

The sample size was determined using the formula:-

$$n = \frac{Z^2 pq}{d^2}$$

n = minimum sample size

Z = confidence limit at 95% of standard normal curve = 1.96

p = prevalence of students of Bayero University and Federal College of Education kano, Nigeria that had a correct perception of what sickle cell anaemia is, which was found to be 14% So p = 0.14

q = 1 – p = 1 – 0.14 = 0.86 d = degree of precision = 0.05(5%)

Therefore,

$$n = \frac{1.96^2 \times 0.14 \times 0.86}{(0.05)^2}$$

$$n = \frac{0.4625}{0.0025}$$

$$n = 185$$

$$n = 185$$

This was increased to 200 so as to allow for loss due to non-response.

3.5 SAMPLE SELECTION

Dala local government area Kano was selected through simple random sampling technique for study from among the 44 LGAs in Kano State.

A simple random method of sampling was used to select the youths on which the available questionnaires were administered.

3.6 PREPARATION FOR THE STUDY

An introduction letter was obtained from the Department of Community Medicine addressed to the district head and the local government secretariat involved in the study to seek for permission to conduct the study in the area.

3.7 DATA COLLECTION TECHNIQUE

A questionnaire was designed to obtain information on socio-demographic characteristics (personal data), respondents' knowledge of sickle cell anaemia, and identify respondents attitude towards premarital genotype counseling and screening

3.8 DATA ANALYSIS

The data collected was presented in the form of tables and graphs (pie charts and bar charts) and was analyzed using SPSS. Statistical test of significance (χ^2) was used to test association between variables.

3.9 ETHICAL CLEARANCE:

Ethical clearance for the study was sought from the department of Community Medicine and Bayero University Kano. Permission was then sought from the relevant authorities in Dala Local Government and Kano state Ministry of Health. Informed consent was obtained from respondents and response to any of the issues raised in the questionare was strictly voluntary. Data collection was by the use of self administered questionnaire and information obtained from respondents was treated with anonymity and utmost confidentiality. Only personal information and demographic data relevant to the study was obtained from the respondents

CHAPTER FOUR

RESULT

SECTION A: SOCIODEMOGRAPHIC CHARACTERISTICS

Table 1.0 Age distribution of the respondents

VARIABLES	Frequency	Percent
15-16	25	13.2
17-18	48	25.3
19-20	15	7.9
21-22	5	2.6
23-24	97	51.1
Total	190	100.0

The result of the analysis shows that 51.1% of the respondents fall between the ages of 23-24.

The mean age is **20.57** and standard deviation is **3.056**.

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Figure1. 1 Gender distribution of the respondents.66% are male and 34% are female

Figure1. 2 Marital status of the respondents, 96% are single and Only 4% are married

Figure 1.3 Religious affiliation of the respondent. 96.5% are Muslim while 3.5% are Christian

Figure1.4 Tribal distribution of the respondents.

Figure1.5 The occupational distribution of the respondents. 92% are students

Figure 1.6 Level of education of respondent

Majority of the respondent 41% has secondary school as their highest level of education, 30% tertiary, 8.5% primary, 16.5% quranic and 4% none

SECTION B: KNOWLEDGE OF SICKLE CELL ANEMIA

Figure 2.1 Distribution of the respondents that have/have not heard of sickle cell disease

Among the respondent 83% have heard of sickle cell disease and 17% have not heard about sickle cell disease

Figure 2.2 Respondents' understanding of sickle cell disease

Figure 2.3 Respondents knowledge on mode of acquisition of sickle cell disease

Most of the respondents (43%), are of the opinion that inheritance from parents to be the correct way of SCD transmission. 24% individuals believe that it is transmitted by infection of the mother during pregnancy, 19% respondents are of the opinion that SCD is transmitted through infection of the child after birth, while 1.3% individuals have no idea about the mode of transmission of SCD

Figure 2.4 Respondents have heard of sickle cell carrier.

Most of the respondent 83.5% have heard about sickle cell carrier, only 16.5% have not heard about sickle cell carrier

Figure2.5 Respondents' knowledge of sickle cell carrier

Majority of the respondent 50.5% believe AS as sickle cell sarrier state, 38% AA ,11% SS and 12% are not sure

Figure 2.6 Respondents' knowledge of complications of sickle cell disease.

36% of the respondent are of the opinion that pain episodes as medical complication,23% stroke, 25% lung tissue disease and 10% all of the above

Figure 2.7 Respondents' knowledge about cure of sickle cell disease.

Figure 2.8 Respondents' knowledge on mode of treatment.

Almost 60% of the respondents are of the opinion that SCD is not a curable disease. 40% believe that the disease is curable. But majority of the respondents believe that medical treatment, traditional treatment, and prayers can provide a cure to the disease.

SECTION C : ATTITUDE AND PERCEPTION TOWARDS PREMARITAL COUNSELING AND SCREENING

Figure 3.1 Respondents knowledge on premarital genotype counseling

Knowledge	Frequency	Percent%
YES	96	51.6
NO	94	49.4
Total	190	100.0

51.6% of the respondent know about premarital genotype counseling and only 49.4% don't know about premarital genotype counseling

Figure 3.2 Respondents opinion on advocating premarital counseling. 47% agree,28% disagree and 25% are not sure.

Figure 3.3. Respondents distribution of those that know their genotype.

33% of the respondent know their genotype and 67% don't know their genotype

Figure 3.4 Respondents knowledge of partner's genotype.

Only 31% of the respondent know their partners genotype, 69% don't know

TABLE 2 IF YOU ARE A SC CARRIER WILL YOU ALSO MARRY A CARRIER

VARIABLES	Frequency	Percent (%)
YES	52	27.4
NO	134	70.5
I DON'T KNOW	4	2.1
Total	190	100.0

Only 27.4% of the respondents as carrier will also marry a carrier and 70.5% will not

Figure 3.6 Respondents' opinion on recommending premarital counseling.

Figure 3.7 Respondents' belief concerning their religion and premarital counseling.

TABLE 3 Overall grading knowledge of respondents

knowledge	Frequency	Percent(%)
poor	81	42.6
fair	54	28.4
good	55	28.9
Total	190	100.0

TABLE 4 RELATIONSHIP BETWEEN KNOWLEDGE AND SEX

Gender	KNOWLEDGE			Total
	poor	Fair	Good	
male	61	30	41	132
female	20	24	14	58
Total	81	54	55	190

Chi-square value=6.9, df=2, p value=0.032

There is significant association between gender and knowledge of sickle cell disease with males having better knowledge.

Table 5. RELATIONSHIP BETWEEN KNOWLEDGE AND AGE GROUP

AGE GROUP	KNOWLEDGE GRADE		Total
	POOR	GOOD	
15-16	10	15	25
17-18	20	28	48
19-20	4	11	15
21-22	0	5	5
23-24	47	50	97
Total	81	109	190

Chi-square value=6.712, df=4, p value=0.152

There is no significant association between age and knowledge of sickle cell disease.

Table 6. RELATIONSHIP BETWEEN KNOWLEDGE AND EDUCATIONAL STATUS

EDUCATIONAL STATUS	KNOWLEDGE			Total
	poor	Fair	Good	

None/pri.	2	8	6	16
Sec.	41	33	8	82
Tertiary	38	13	41	92
Total	81	54	55	190

Chi-square value=36.344, df=4, p value=0.000

TABLE 7 OVERAKK ATTITUDES OF RESPONDENTS

Attitude	Frequency	Percen
NEGATIVE	164	86.3
POSITIVE	26	13.7
Total	190	100.0

Table 8. RELATIONSHIP BETWEEN ATTITUDE AND GENDER

		ATTITUDE		Total
		negative	positive	
GENDE	Male	115	17	132
R	Female	49	9	58
Total		164	26	190

Chi-square value=0.237, df=1, p value=0.626

There is no significant association between gender and attitude toward sickle cell disease.

Table 9. RELATIONSHIP BETWEEN ATTITUDE EDUCATIONAL STATUS

	ATTITUDE		Total
	Negative	Positive	
PRI/Quranic	13	3	16
Secondary	76	6	82
Tertiary	75	17	92
Total	164	26	190

Chi-square value=4.952, df=2, p value=0.084

There is no significant association between level of education and attitude toward sickle cell disease.

CHAPTER FIVE

5.0 DISCUSSIONS

The sample consisted of 190 respondents. All of them within the age group 15-24 years(youth age), majority of the respondents (51%) fall within the age group 23-24 years. This is because 23-24 years age group is the predominant age group commonly found in tertiary institutions or have completed secondary school as such are able to read and fill the questionnaire correctly. The few respondents within 17-18 years age group are likely to comprise of secondary school graduates who are awaiting their result and so are available at home at the time of the research.

Majority of the respondents 66% were males with only 34% being females. This can be attributed to the fact that more males were available outside their homes to respond to the interview than the females who are mostly at home, and also to the fact that enrolment of females into institutions is still low in this part of the country due likely to some traditional and cultural beliefs.

Hausa/Fulani was the predominant ethnic group (98%), then Yoruba and Igbo constituting the remaining 2%. This is because Hausa/Fulani is the dominant ethnic group in Kano and most of the other nearby states.

Similarly, most of the respondents were Muslims (98.4%) with the remaining being Christians, this is because Islam is the predominant religion in this part of the country. The reverse is the case with a similar study in Ebonyi state University southern Nigeria where 98.2% of the respondents were Christians

The vast majority of the respondents (96%) were single, with few (4%) married, this could buttress the fact that majority of the Nigerians at this age are students and marry after graduation probably because of financial constrain. Also, most of the respondents (79.5%) have some formal education with majority attending secondary and tertiary institutions, while only 20.5% have no formal education reflecting the increase awareness of the society on the importance of formal education.

Majority of the respondents (83%) were aware of sickle cell disease and 17% have not heard about SCD at all, only 43% knew that it is inherited from parents (genetic disorder). This is not in consistent with a study carried out at the Department of Emergency Medicine, Vanderbilt University school of Medicine, Nashville, Tennessee, where out of 147 black patients presenting to the emergency department with minor medical condition interviewed 98% of them heard 73% knew that it was a genetic disorder³⁷. However, few of the respondents (12%) had no idea about the cause of the disease, while some (32%) felt that the disease could be caused by maternal infection during pregnancy and infection of child after birth, others believe it is a fatal illness. Almost 40% of the respondents were of the opinion that SCD is not a curable disease. But majority of the respondents believe that medical treatment, traditional medications and prayers can provide cure to the disease. Others even suggested that Traditional medication and spiritual incantation provide cure to SCD patients. This poor perception about the curability of SCD tends to make people with that notion to underestimate the burden of the disease with consequent poor attitude about the disease prevention.

With regards to knowledge, only 42.6% have good knowledge about sickle cell disease despite high level of awareness of 83% (from figure 2.1), which is consistent with a similar study conducted among youth corps members in Benin city where only 17.8% had good knowledge despite 98% awareness level⁵. Meanwhile 32.7% of the respondents have

From figure 2.1 it showed that majority (51%) of the respondents are aware of premarital counseling, while 49% are not aware. This is similar study done in Plateau state which shows that 50.7% are aware and 49.3% are not aware. This is likely due to the fact that majority of the respondent have low level of awareness as among the youth community in Plateau³ study as the participants comprises of youth of different level of education. Similarly (33%) of the respondents know their genotype, this is not comparable to a similar study among youth corps

members in Benin city which showed that majority 94.6% of the participants know their hemoglobin genotype status⁵. On whether participants know their partner's genotype, figure 3.4 only about a third (31%) know their partner's hemoglobin genotype status, this however is not the case in a similar study performed among local government workers in Ile Ife where about two-third (74.5%) of the participants knew their partner's genotype status¹⁹. This could be attributable to respondents' ethnicities since most of the respondents are Hausas and not culturally inclined to have the premarital counseling. On the question whether the respondent will still go on to marry his/her partner even when their genotype status shows possibility of having a child with sickle cell, figure 3.5 showed that about half (27.4%) will still go on to marry. This is not consistent with similar study carried out from 207 mothers (out of them 60.4% of the mothers had secondary education) attending the infant welfare and antenatal clinics of Nnamdi Azikiwe University Teaching Hospital, Nnewi on knowledge of the existence of sickle cell disease, attendance at marriage counseling sessions, knowledge of own and husband's genotype before marriage. Only one hundred and fifteen or 55.5% had knowledge of their genotype and that of their husbands. While 23.7% and 13.5% of them knew their genotypes before courtship and during courtship respectively, 34.3% knew theirs before wedding and only 7.2% knew after wedding ⁶².

With regards to the attitude only 13.7% have positive attitude and 86.3% have negative attitude, this may be attributed to socio cultural background and low level of awareness of the respondents.

LIMITATIONS

1. Cultural influences and religious beliefs may hinder some of the respondents from giving objective responses and thus the sincerity of the responses may not be guaranteed
2. Some of the terminologies used in the questionnaire were not easily understood by some of the respondents.

CHAPTER SIX

6.0 CONCLUSION

This study has shown that there is a deficiency in the knowledge and attitude about sickle cell disease among youths of Dala LGA in Kano especially with regards to the concept of the disease, mode of transmission. The attitude of the respondents toward knowing their hemoglobin genotype as well as that of their sincere boy/girlfriends is very poor. This finding is not unexpected considering

In order to reduce the incidence of the disease, increasing public awareness about the disease more especially those in secondary and tertiary institutions as well as provision of free genetic screening, premarital counseling and testing, counseling of the affected individuals and educating them about the disease need to be emphasized.

6.1 RECOMMENDATIONS

1. For education and prospective carrier identification and genetic counseling with minimal emotional pressure and at minimal cost to be feasible, youths who are not yet committed to relationship, may be an ideal target group to begin with. Fortunately this segment of the population is usually well concentrated in institutions of higher learning where mass access should not be a problem. Although it is not easy to change people's behavior in choosing partners, it is still preferable that young people should know their hemoglobin status before entering marriage or courtship. Hemoglobin genotype determination and genetic counseling of youth at this level is most timely because it offers the best chance of influencing their mate selection conduct and also prepares them for appropriate reproductive choices later.
2. There is a need to embark on public enlightenment and health education on sickle cell disease and ways of preventing it through mass media (TV, Radio programs, e.t.c), health talks in PHC centers, use of posters and banners, in newspapers and magazines, public lectures, health campaigns, seminars, symposia, e.t.c., which will help improve awareness of the general public about sickle cell disease.

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SAMPLE QUESTIONNAIRE

DEPARTMENT OF COMMUNITY MEDICINE, COLLEGE OF HEALTH SCIENCES

BAYERO UNIVERSITY KANO

FINAL YEAR PROJECT QUESTIONNAIRE

**TOPIC: KNOWLEDGE OF SICKLE CELL ANEMIA, ATTITUDE AND PERCEPTION
TOWARDS PREMARITAL GENOTYPE COUNSELLING AND SCREENING AMONG
YOUTHS OF DALA L.G AREA KANO, NORTHERN NIGERIA.**

I am Saidu Idris Ahmad, a final year medical student of Bayero University
Kano/Aminu Kano Teaching Hospital, conducting a research on the above topic as a
partial fulfillment of the requirements for the award of *MBBS DEGREE*

.The information you are going to provide is for research purpose only, and will be treated with
utmost confidentiality. Also note that participation is fully voluntary and you can withdraw at
any time if you so wish. Thank you.

SECTION 1: SOCIODEMOGRAPHIC CHARACTERISTICS

1.1 Age in years-----

1.2 Sex a. male () b. female ()

1.3 Marital status a. Single () b. Married () c. Divorced () d. Separated () e.
Widowed ()

1.4 Religion a. Islam () b. Christianity () c. Others (specify) -----

1.5 Tribe a. Hausa () b. Fulani () c. Igbo () d. Yoruba () e. Others (specify)

1.6 Occupation (if any).....

1.7 . Level of education:- a. None () b. Quranic only() c. primary () d. Secondary () Tertiary

SECTION 2: KNOWLEDGE OF SICKLE CELL ANEMIA

2.1 Have you ever heard of sickle cell disease?

(a) Yes (b) No

2.2 If 'yes to above' what do you understand by sickle cell disease?

- (a). It's an Inherited blood disorder (b). It's an Infectious disease (c). It's a Sexually transmitted disease
(d). It's a fatal illness

2.3 How does a person get sickle cell disease?

- (a) Infection of the mother during pregnancy (b) Infection of the child after birth
(c) Contact with the infected person (d) Punishment for sin/wrong doing (e) Hereditary (inherited from parents)
(f) I don't know

2.4 Have you ever heard of the term "sickle cell carrier"?

- (a) Yes (b) No

2.5 What genotype is called sickle cell carrier?

- (a) AS (b) AA (c) SS (d) I don't know

2.6 What medical complications are caused by sickle cell disease?

- (a). Stroke (b). Lung tissue damage (c). Pain episode (d). All of the above

2.7 Is there a cure for sickle cell disease?

- (a). Yes (b). No

2.8 If 'yes' how?

- (a) Medical treatment (b) Traditional medicine (c) Spiritual incantations (d) Prayers
(e) Others
(specify).....

SECTION 3 ATTITUDE TOWARDS PREMARITAL GENOTYPE COUNSELLING AND SCREENING

3.1 Do you know about premarital sickle cell counseling?

- (a). Yes (b). No

3.2 Is it good to advocate premarital counseling for all couples intending to get married

- (a). Yes (b). No (c) . Not sure

3.3 Do you know your own Hemoglobin genotype?

- (a) Yes (b) No

3.4 Do you know the Hemoglobin genotype of your serious boy/girl friend?

- (a) Yes (b) No

3.5 Would you still go on to marry your partner even when the genotype result shows possibility of having a child with sickle cell disease?

(a). yes (b). No

3.6 Would you recommend premarital counseling to an intending couple?

(a) Yes (b) No

3.7 Is premarital counseling against your religious belief?

(a) Yes (b) No

Thanks for your time