KNOWLEDGE AND PERCEPTION OF OUT-OF-SCHOOL YOUTHS ON SICKLE CELL DISEASE IN IBADAN NORTH EAST LOCAL GOVERNMENT AREA, OYO STATE

BY

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ABSTRACT

Sickle cell disease (SCD) is a genetic disorder that affects a considerable number of individuals and its impact reduces economic productivity. Young persons with this disease often experience vaso-occlusive crises, aneamia and are often susceptible to infections. There is dearth of correct information about SCD in Nigeria, especially among the out-of-school youths because of the sparse nature of the population. This study was therefore designed to investigate on the knowledge and perception of out-of-school youths on SCD in Ibadan North East Local Government Area of Oyo State, Nigeria.

The study was a descriptive cross-sectional survey. Cluster sampling was used to choose the locations for the study and participants were selected during each visit using convenient sampling. An interviewer-administered questionnaire which included a 49-item was used to elicit information on the respondents' socio-demographic characteristics, knowledge of sickle cell disease and perception. The total knowledge score was 11. Knowledge scores 0-5, >5-8, and >8 were categorized as poor, fair, and good knowledge respectively. The total perception score was 20. Perception scores 0-5, >5-10, and >10 were categorised as negative, lukewarm, and positive perception, respectively. Data were analysed using descriptive and inferential statistics at 5% level of significance.

Mean age of the respondents was 20.8±2.2 years. More than half (58.6%) of the respondents were males, while (41.4%) were females. Majority (72.6%) of the respondents were of the Yoruba ethnic group. Almost all (94.4%) of the respondents were aware of SCD, friends and family (50.1%) were their main sources of information. Most (88.9%) of the respondents were not aware of sickle cell trait (SCT). Some (40.4%) of the respondents had done a blood genotype test. Almost all (92.8%) of the respondents did not know how SCD is confirmed or diagnosed. A considerable number of the respondents (57.4%) did not know how SCD is acquired. Few (38.1%) had poor knowledge about SCD, half (50.5%) had fair knowledge, and few (11.1%) had good knowledge about SCD, with a mean knowledge score of 4.1±2.1. There is no statistically significant relationship between age, religion, ethnicity, marital status, educational level and occupation of respondents and their knowledge on SCD. Positive SCD related perceptions

included the following views: Knowing my SCD status can influence my decision to marry (86.0%); anybody can carry the sickle cell gene (54.7%); while the negative perception views included: SCD is not a serious disease, it is only overemphasized (26.7%); and SCD can be prevented by eating good food (41.7%). Few (10.1%) of the respondents had negative perception, half (51.5%) had lukewarm perception and a considerable number (38.4%) had positive perception. Association between respondents' gender and perception was statistically significant at p=0.001.

Knowledge about sickle cell disease is generally fair, however despite fair knowledge; respondents had negative perceptions and misconception about the causes, means of acquisition and prevention of sickle cell disease. Public enlightenment and frequent health education at the community level is recommended to upgrade their knowledge and reduce misconceptions, these will help in improving positive perception on sickle cell disease amongst this population.

Keywords: Out-of-school youths, sickle cell trait, sickle cell disease and genotype.

Word count: 49

iii

DEDICATION

This report is dedicated to God Almighty who has given me the grace to embark on this

ACKNOWLEDGEMENT

My sincere gratitude goes out to my wonderful supervisor, Dr. M.A. Titiloye, of the Department of Health Promotion and Education, Faculty of Public Health, College of Medicine, University of Ibadan, Oyo State, who was never tired of me, and always made sure I towed the right path in compilation of this write-up, I am indeed grateful sir, God will continue to bless you. My heartfelt gratitude also goes to all members of staff; both academic and non-academic for their unwavering support, I am most grateful. To Mr. John Emaledo, I cannot thank you enough, but the Lord who sees your good works in secret will abundantly reward you in the open. I will like to appreciate all my colleagues for always helping me solve one problem or the other during the compilation of this project. My sincere appreciation also goes to Mr Alalade Akinola, and all my Team members (those Dr Titiloye supervised) for your contributions in making this write-up a success.

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To the people suffering from Sickle cell disease, may the mercy of the Lord continue to sustain you and strengthen you to lead healthier lives. I thank God Almighty for making this project work a success, without whom, I would have been able to do nothing.

CERTIFICATION

I hereby certify that Miss Gansari Beatrice Bona of the Department of Health Promotion and Education, Faculty of Public Health, College of Medicine, University of Ibadan, Oyo State, carried out the studies in this project report under my supervision.

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TABLE OF CONTENTS

Title p	page i
Abstra	netii
Dedica	ationiv
Ackno	owledgement
	ication vi
Table	of contentsvii
	f tablesix
List of	f figures x
	f appendices xi
List of	f abbreviations xii
Opera	tional definition of termsxiii
	\\\\\\\\\\\\\\\\\\\\\\\\\\\\\\\\\\\\\
CHAI	PTER ONE: INTRODUCTION
1.1	Background
1.2	Statement of problem
1.3	Justification of the study4
1.4	Research questions5
1.5.1	Broad objectives
1.5.2	Specific objectives
1.5.3	Research hypotheses5
CHAI	PTER TWO: LITERATURE REVIEW
2.1	Concept of Sickle Cell Disease6
2.2	Inheritance6
2.3	Knowledge of sickle cell disease9
2.4	Perception on Sickle Cell Disease
2.5	Perception of Respondents on Prevention of Sickle Cell Disease
2.6	Conceptual framework

СНА	APTER THREE: METHODOLOGY	
3.1	Study design	14
3.2	Study area	14
3.3	Study population	15
3.4	Sample size	15
3.5	Sampling technique	16
3.6	Method of data collection	16
3.7	Validity of instrument	16
3.8	Reliability of instrument	17
3.9	Data management and analysis	17
3.9	Ethical considerations	18
СНА	APTER FOUR: RESULTS	
4.1	Respondents knowledge on Sickle Cell Disease and Sickle Cell Trait	23
4.2	The perception of respondents on Sickle Cell Disease	44
4.3	Respondents perception on preventing Sickle Cell Disease	
4.4	Test of hypotheses	49
СНА	APTER FIVE: DISCUSSION, CONCLUSION AND RECOMMENDATIONS	
5.1	Socio-demographic profile of the respondents	52
5.2	Awareness and knowledge about Sickle Cell Disease	52
5.3	Perception of respondents on Sickle Cell Disease	54
5.4	Perception of respondents on preventing Sickle Cell Disease	55
5.5	Implication for Health Promotion and Education	.55
5.6	Conclusion	56
5.7	Recommendation	57
REF	ERENCES	58
	FNDICES	61

LIST OF TABLES

Table 2.1: Two parents have SCD	8
Table 2.2: One parent has SCD and SCT	8
Table 2.3: One parent has SCD and the other parent carries normal genes	8
Table 2.4: Two parents have sickle cell trait	9
Table 2.5: One parent has Sickle Cell and the other is normal	9
Table 4.1a: Socio-demographic characteristics of respondents	
Table 4.1b: Distribution of respondents' occupation	22
Table 4.2: Respondents' awareness and sources of information on SCD and SCT	26
Table 4.3: Respondents' knowledge about personal blood genotype	
Table 4.4: Respondents' blood genotype distribution	28
Table 4.5: Respondents' reason for doing the blood genotype test	
Table 4.6: Reasons for not doing personal blood genotype	30
Table 4.7: Respondents' readiness to do blood genotype test	31
Table 4.8: Respondents' ability to identify an individual with SCD	32
Table 4.9: Respondents' knowledge on confirming SCD in an individual	
Table 4.10: Respondents' family history of Sickle Cell Disease	34
Table 4.11: Respondents' knowledge about how SCD is acquired	35
Table 4.12: Respondents knowledge on signs and symptoms of SCD	36
Table 4.13: Respondents' knowledge on the physical features of an individual with SCD	
Table 4.14: Respondents' knowledge about conception with SCD	38
Table 4.15: Knowledge of respondents' on causes of SCD and diagnosis	39
Table 4.16: Respondents' knowledge on the genotype of children whose parents	
have Sickle cell trait and sickle cell disease	40
Table 4.17: Respondents' knowledge on medications used to relief pain in SCD persons	41
Table 4.18: Respondents' perception on Sickle Cell Disease	43
Table 4.19: Respondents' perception on preventing Sickle Cell Disease	44
Table 4.20: Relationship between respondent' socio-demographic characteristics	
and their knowledge scores on SCD	45
Table 4.21: Relationship between respondent' socio-demographic characteristics	
and their perception scores on SCD	46

LIST OF FIGURES

Figure 2.6: Health Belief Model
Figure 4.1: Levels of knowledge among respondents on Sickle cell disease
Figure 4.1: Levels of knowledge among respondents on Sickle cell disease

LIST OF APPENDICES

Appendix I: Questionnaire (English version)
Appendix II: Questionnaire (Yoruba version)
Appendix III: Ethical approval from Oyo State Research Ethical review Committee74
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LIST OF ABBREVIATIONS

SCD - Sickle cell disease

 $\mathbf{H}\mathbf{b}^{\mathbf{c}}$ - Hemoglobin C $\mathbf{H}\mathbf{b}^{\mathbf{E}}$ - Hemoglobin E

Hb^A - Hemoglobin

SCT - Sickle cell trait

ACS - Acute Chest Syndrome

WHO - World Health organization

AYP - Adolescents and young persons

SCA - Sickle cell anemia

HbSC - Hemoglobin SC

HbSS - Hemoglobin SS

HbF - Fetal hemoglobin

UNAIDS - United Nations Programme on HIV/AIDS

OPERATIONAL DEFINITION OF TERMS

Sickle cell disease: An inherited disorder of the red blood cells in which one gene is for sickle hemoglobin (S) and the other gene is for unusual hemoglobin such as S, C, Thal (SCDAA,2005;UMMC,2010).

Out-of-school youth: The term "out-of-school youth" is used to define several groups of young people; those who have dropped out of school; those who never attended school, or those who participate in non-formal school programs (Burns and Ruland, 2004).

CHAPTER ONE

INTRODUCTION

1.1 Background

Sickle Cell Disease (SCD) is an inherited disorder of the red blood cells in which one gene is for sickle hemoglobin (S) and the other genes is for unusual hemoglobin such as S, C, Thal (Sickle Cell Disease Association of America, 2005; University of Maryland Medical Center, 2010). SCD also describes a cluster of inherited red blood cell disorders. All forms of the disease have in common a tendency for the red blood cells to distort to a crescent shape (sickle shape) under certain conditions. Individuals with SCD have abnormal hemoglobin called hemoglobin S or sickle hemoglobin in their red blood cells. Those who have SCD inherit two abnormal hemoglobin genes, one from each parent. In all forms of SCD, at least one of the two abnormal genes causes a person's body to make hemoglobin S. When a person has two hemoglobin S genes, Hemoglobin SS, the disease is called sickle cell anemia (SCA); Hemoglobin SC disease and hemoglobin Sβthalassemia (thal-uh-SEE-me-uh) are two other common forms of SCD in Africa (National Institute of Health, 2017).

Sickle cell trait also known as Sicklemia is a condition in which an individual is a carrier of the gene that causes sickle cell disease but does not display the severe symptoms of the sickle cell disease (American Society of Hematology, 2015). Sickle cell trait is not a disease and people with this trait can enjoy a normal life but can pass the gene to their offsprings (American Society of Hematology, 2015). Two parents with sickle cell trait have a 25% chance of having children with SCD and a 50% chance of having children with SCT (Olarewaju, Enwerem, Olakekan and Olugbenga, 2013). To reduce the transfer of the abnormal genotype, it is highly recommended that people in their reproductive age group understand the genetics of SCD, know their blood genotype, and if they carry the S gene, choose partners in advance with normal hemoglobin genotype to prevent procreation of children with the disease and to reduce the prevalence of SCD (Olarewaju et.al., 2013).

Nigeria accounts for 50% of the SCD births worldwide with 2.3% of the population suffering from SCD and 25% being carriers of the SCT, (Oludare and Ogili, 2013). Africa is home to a large population of individuals affected with SCD. Nigeria has the highest concentration of patients with sickle cell anemia in the whole world (Juwah, Nlemadim and Kaine, 2004). SCD has remarkable public health implications for Africa. It contributes the equivalent of 5% to under-five deaths in Africa, with up to 16% in West Africa (Weatherall and Clegg, 2001). Thus in Nigeria, with an estimated carrier prevalence of 24%, 20 per 1000 births are estimated to be affected by SCD, resulting in 150,000 children with SCD born annually in Nigeria (WHO, 2006).

The increasing number of SCA will continue to have a major impact particularly on health care services and financing (Piel, Hay, Gupta, Weatherall, and Williams, 2015). Prevention of sickle cell disease is a very important factor in the reduction of its burden, but most importantly, premarital counseling has shown to have a significant advantage over neonatal screening, in that while the former is aimed toward primary prevention, the latter addresses secondary or tertiary prevention (Lal and Vichinsky, 2005). A number of the Mediterranean and Middle Eastern countries have developed effective premarital counselling and testing protocols with a view to reducing high-risk marriages with some interesting results (Memish and Saheed, 2011).

Around 89 million youths, ages 12-24 years, are out of school in sub-Saharan Africa (World Bank, 2015). The term "out-of-school youth" is used to define several groups of young people: those who have dropped out of school, those who never attended school, or those who participate in non-formal school programs (Burns, Ruland and William, 2004). Majority of out-of-school youths hawk on the street, engage in menial jobs, learn a trade, or skills, some stay at home for housework or child care or are unemployed. Many out-of-school youths lack access to health care and education and they suffer from physical and psychological abuse, unintended pregnancies, poverty, stigmatization and gender-based violence (United Nations Programme on HIV/AIDS, 2014). The Permanent Secretary, Federal Ministry of Education, Adamu Hussaini, has disclosed that Nigeria has the highest number of out-of-school children in the world. According to him, this percentage represents 10.5million of the cumulative 20 million out of school children in the world (Guardian, 2018).

SCD is not commonly cured, but mostly managed throughout the life time of the patient, especially in developing countries where uniform methods of managing those with the disease, cure for the disease and poverty is still prevalent. There is a need to know the level of knowledge and perception of the youths that are out-of-school who constitute a significant proportion of the population, to enable adequate prevention of the disease and also to enable a reduction on the incidence of morbidity and mortality caused as a result of this disease. Looking into the knowledge and perception of sickle cell disease among out-of-school youths will be of much importance because this is the period when people within this age group make marital choices.

A prior knowledge of SCD and its impact on affected individuals and offspring might enhance positive attitude toward its prevention. This study investigated on; the knowledge and perception of sickle cell disease among out-of- school youths in Ibadan North East Local Government Area, Oyo State.

Sickle cell disease is a chronic, multisystem disease. In spite of decades of medical advances in SCD management, studies have revealed an increased risk of stillbirth, preterm delivery and small for gestational age, maternal mortality and preeclampsia, compared to the general population (Rogers, Neerujah, Awogbade and Johns, 2019).

1.2 Statement of the problem

Nigeria has the highest prevalence of SCD in the world with 40 million carrying the genes. The incidence of SCD in Nigeria is among the highest in the world with more than 100,000 children being born each year with the disorder and those with the disease suffering higher than average frequency of illnesses and premature death (Sickle Cell Aid Foundation, 2015). Sickle cell disorder has been acknowledged to have a global impact by the World Health Organization (World Health Organization, 2006). Patients with Sickle cell anemia have numerous acute and chronic medical problems, which collectively contribute to life threatening morbidity, early mortality and annual domestic medical costs exceeding \$1.1billion (Therrell and Lloyd-Puryear, 2015). Millions of persons throughout the world are living with and unfortunately dying from this inherited blood disorder without the benefits of proper diagnosis and appropriate clinical care.

World-wide more than three hundred thousand infants are born with Sickle cell anemia (Piel, Patil and Howes, 2013). Nigeria has a high prevalence of SCT, impacting an estimated 25 % of adult population (Ezenwosu, Chukwu, Ikefuna, Hunt and Keane, 2015). The prevalence of HbSS is 1-3% and it poses a severe burden on the affected individuals and their families (Olarewaju, Enwerem, Adebimpe and Olugbenga, 2013). In spite of the high prevalence of both SCT and SCA in Nigeria, several people are still not aware of its presence and its significance in contributing to the burden of disease in Nigeria (Piel, Patil, and Howes, 2013).

There is no universal newborn screening programme, no continuous sensitization about the disease, no uniform premarital testing for sickle cell genotype in Nigeria, which results in children with sickle cell disease being identified during an illness when genotype is tested on clinical suspicion, in most cases, this is also the time when the genotypes of their parents are discovered (Piel, Gupta, Weatherall and Williams, 2013). This dramatic projection indicates the need to identify methods to increase awareness and educational levels related to SCT and SCA. The most appropriate time for individuals to become aware of their sickle cell genotype is before conception.

1.3 Justification

Knowledge about SCD could be a great determinant to the perception of an individual about the disease. There is death of correct information about SCD especially among out-of-school youths because of the sparse nature of the population. Sickle cell disease lowers quality of life for thousands of African families. The disease is a genetic disorder that is preventable by marriage between genetically compatible spouses, proper genetic counseling and health education before marriage. Very many studies about sickle cell disease have been conducted amongst different populations, like the undergraduates, youths, parents, secondary school students, but the out-of-school youths have been neglected and they constitute a considerable number of the population in Nigeria. This age group have a higher number of people going into marriage, conducting a research amongst them can enhance the prevention of SCD among this population, thereby helping to reduce the prevalence of the disease in Nigeria.

Therefore, assessing the knowledge and perception of SCD, sickle cell inheritance, its health and reproductive health implications particularly among out-of-school youths is of utmost

importance to be able to limit the spread of the disease and control an increase in its prevalence. The aim of this study is to assess the knowledge and perception of out-of-school youths on sickle cell disease in Ibadan North East local government area in Oyo State.

1.4 Research questions

- 1. What is the level of knowledge of out-of-school youths in Ibadan North East Local Government Area on sickle cell disease?
- 2. What is the perception of out-of-school youths in Ibadan North East Local Government Area on sickle cell disease?
- 3. What is the perception of out-of-school youths on prevention of sickle cell disease?

1.5 Objective of the study

1.5.1 Broad objective

The broad objective of the study was to investigate the knowledge and perception of outof-school youths on sickle cell disease.

1.5.2 The specific objectives of the study were to:

- 1 Assess the knowledge of out-of-school youths on sickle cell disease.
- 2 Describe the perception of out- of- school youths towards sickle cell disease.
- 3 Document the perception of out-of-school youths about prevention of sickle cell disease.

1.5.3 Null hypotheses

- **Ho I**. There is no significant relationship between the socio-demographic characteristics of the respondents and their knowledge about sickle cell disease.
- **Ho II**. There is no significant association between the socio-demographic characteristics of the respondents and their perception on sickle cell disease.

CHAPTER TWO

LITERATURE REVIEW

2.1 Concept of Sickle Cell Disease

Sickle cell disease (SCD) includes a variety of pathologic conditions resulting from inheritance of sickle hemoglobin (Hb) either in a homozygous state (SS) or in a heterozygous state with abnormal hemoglobin such as SC, Sβthal, SOArab, SD and SG (Aken'ova, 2013). Sickle cell anemia (SCA) and Hemoglobin SC disease (HbSC) are the two most frequent types of SCD and both are hereditary diseases with an autosomal recessive pattern of inheritance (Afolayan and Jolayemi, 2011).

SCA is caused by a structural variant of the major adult hemoglobin called S or Sickle hemoglobin (HbS), while HbSC is caused by the presence of two variants, one of them is sickle hemoglobin and another is hemoglobin C (HbC) this variants result from HbS and HbC allelic genes in beta globin locus in chromosome 11p. HbS allele differs from the normal allele A, in a single amino acid; at position 6 a valine replace a glutamic acid residue, in HbC allele, at the same locus lysine replace glutamic acid residue also at position 6. Affected individuals with SCA are homozygous SS, because they inherit one HbS allele from each parent; while affected individuals with HbSC are heterozygous SC, because they inherit one HbS allele from a parent and one HbC allele from another parent (Afolayan and Jolayemi, 2011).

The main pathology in SCD is the trapping of sickle shaped red cells in small blood vessels resulting in blockages. This typically manifests as bone pain, which is one of the most distressing symptom in people affected by SCD (Olanrewaju et al., 2013).

Inheritance

Sickle cell disease is a recessive gene and if two parents have two copies of the Hb^s gene, their children will have Sickle cell disease (Table 2).

Two parents have Sickle cell disease

	S	S
S	SS	SS
S	SS	SS

S=Hemoglobin S, SS=Hemoglobin SS

Table 2.1: Two parents with SCD

One parent has SCD and the other parent carries SCT

Table 2.2 show that one parent has the SCD Hb^S genes meaning that all of that parent's gametes will carry the Hb^S gene. The other parent has one Hb^S gene and one Hb^A gene. The chances for that parent with both the HB^S gene and the Hb^A gene transmitting either gene are equal, or 50/50 (Bloom, 1995). All children born to these parents will have either SCD or SCT children with the chances been half for each birth.

	S	S
A	AS	AS
S	SS	SS

A=Hemoglobin A, AS=Hemoglobin AS

Table 2.2: One parent has SCD and SCT

One parent has SCD and the other parent carries normal genes

Table 2.3 illustrates that the Hb^A gene is carried by the normal parent and the gametes from this parent will carry this particular gene, as well as the SCD parent carrying the Hb^S gene (Bloom, 1995). All children conceived from these parents will inherit one normal and one sickle cell gene. All children will have the SCT.

	S	S
A	AS	AS
A	AS	AS

Table 2.3: One parent has SCD and the other parent carries normal genes

Two parents have SCT

Table 2.4: Show that both parents have an equal chance of transmitting the two genes. If both parents have the SCT, they will have a 25% chance of having children with SCD, as well as a 50% chance of carrying the SCT (Bloom, 1995). Also a slight 25% chance occurs of having children with normal genes. In this case, 50% of the time, one parent will transmit HbS gene, and the other half of the time the other parent will transmit an Hb^A gene (Bloom, 1995).

	A	S
A	AA	AS
S	AS	SS

A=Hemoglobin A, AA=Hemoglobin AA

Table 2.4: Two parents has sickle cell trait

One parent has SCT and the other is normal

All children from this table above will display the SCT/normal genes, and the other half of the gametes of the parent who carries the SCT will carry the HbS gene, and the other half will carry the Hb^A (Bloom, 1995). This combination will result in a 50/50 chance of producing a child with normal genes or inheriting SCT.

	A	S
A	AA	AS
A	AA	AS

Table 2.5: One parent has Sickle Cell and the other is normal

2.2 Knowledge of sickle cell disease

Knowledge about sickle cell disease among youths could constitute an important variable that influences their premarital attitude and behavior (Olanrewaju et al., 2013). Education and genetic counseling is a very important variable in improving the knowledge of sickle cell trait and SCD (WHO 2006; Ezenwosu et al., 2015). According to a study by Moronkola and Fadairo (2007), majority do not know their genotype and even in the University where genotype screening is supposedly included in the medical screening for newly admitted students, only 63.6% of the students knew their genotype. Likewise findings from a study carried out by Osbourne (2011), showed low knowledge about SCD, this is also similar to the study carried out by Boyd, Watkins, Price, Fleming and Debaun (2005). Results from Ogamdi (1994) showed that the basic facts about SCD were not well understood by college students. A study conducted by Siddiqui, Shunk, Batisha, Adames, Ayala and Stis (2012) on the level of knowledge of SCD among students reported a low level of knowledge in Nigeria and some other countries.

The sickle-cell gene has become widespread in Africa because the sickle-cell trait confers some resistance to falciparum malaria during a critical period of early childhood, favouring survival of the host. Subsequent transmission of the abnormal hemoglobin gene, although a single abnormal gene may protect against malaria, inheritance of two abnormal genes leads to sickle cell anemia and confers no such protection, and malaria is a major cause of ill-health and death in children with sickle-cell anemia (WHO, 2006). Though the frequency of sickle cell trait predicts the prevalence of SCA, awareness and knowledge of sickle cell trait status may help reduce the prevalence of SCA (Ezechukwu and Chukwuka 2004; Nnaji et al., 2013; WHO 2006).

It is estimated that a significant proportion of individuals in Nigeria are unaware of their sickle cell genotype prior to marriage (Ezechukwu and Chukwuka 2004). A study on the attitudes and awareness of youths in the Yaba Development Area found that 55% of youths in the age group of 15–19 years old had no exposure to SCA premarital counselling (Oludare and Ogili 2013). This same group also scored lowest in SCA knowledge and had the highest rate of negative attitudes towards SCA (Oludare and Ogili 2013). Despite the large number of people affected with sickle cell disease, the level of knowledge about the disease is still low. Several studies have been conducted on knowledge, perception, attitude, awareness and control practices of SCD, majority of those studies reported poor knowledge about the disease among different

populations. Knowledge about SCD was found to be low in spite of good awareness among respondents in secondary schools and only few knew their haemoglobin genotype (Olanrewaju et al, 2013

Cultural and religious values have significant impact on the attitudes of parents of children with sickle cell disease especially in Nigeria as these variables influence their health behavior in relation to coping strategies as most parents submit to their fate (Anie, Egunjobi and Akinyanju, 2010). Another study conducted by Adewuyi (2000) among fresh University graduates in Ilorin, Nigeria reported poor knowledge of SCD, as only 43% of the respondents showed little understanding of the disease. Similar study conducted in Benin City, Nigeria by Bazuaye and Olayemi, (2009), titled Knowledge and attitude of Senior Secondary School Students in Benin City Nigeria to Sickle Cell Disease reported that majority of the students (55.1%) do not know their genotype and only 18% had some correct idea about SCD. This same study revealed that sustained health education through school curriculum, mass media and health institutions are relevant to influence new graduates to have better knowledge and attitudes towards sickle cell disease and hence enable them to make informed decisions about pro-creation later in life (Olatona, Odeyemi, Onajole and Asuzu, 2012).

The findings of a study conducted on adolescents in Oyo State revealed that many of the respondent does not have the knowledge of sickle cell disease, it also revealed that they don't have the knowledge of their genotype, this may be as a result of lack of awareness and because it is not made compulsory as a requirement in most of our secondary schools. The same study found out that students exhibited negative attitude of discrimination and isolation towards their peers suffering from sickle cell disease (Famuyiwa and Bolatito, 2015).

A comprehensive knowledge about sickle cell disease is inadequate as evidenced by several studies. Some of the respondents were confused about the difference between the carrier state of a disease and the disease state. Olanrewaju et al., (2013) discovered a low knowledge of SCD despite good awareness amongst respondents, but only few knew their hemoglobin genotype and it was suggested that if sickle cell disease control strategies must yield any significant results, there is a need to raise awareness about genotype testing to rule out the presence or absence of SCD in an individual, which in turn will enable genetic compatibility amongst intending couples to prevent offspring with SCD.

The symptoms experienced from SCD cannot be over emphasized. Patients with SCD may have recurrent illnesses, and be hospitalized due to various complications of the disease and the mental agony of the disease is very significant Katibi (2008). Apart from the physical deformities of the patients like protruding abdomen, thin extremities and gnathopathy and frontal bossing, frequent anemia and pain occurs in the bones, usually in the arms, hands, legs, feet, or back and there may also be pain in the chest or stomach which are common in individuals affected by this disease (Olarewaju et al., 2013).

2.3 Perception of individuals on Sickle Cell Disease

Perception is a process by which individuals organize and interpret their sensory impressions in order to give meaning to their environment (Robbins, 2012). Perception is important because peoples' behavior is based on their perception of what reality is, not on reality itself. There are many reasons why perception varies and this could be due to the observer's individual personality and context, the target being observed and the situation in which the perception takes place (Robbins, 2012). A study conducted by Treadwell and Vinchinsky reported that a few of the respondents had a perception that SCD is acquired through blood transfusion and was contagious (Treadwell, and Vinchinsky, 2006). Cornelius, Angels, Joseph, Bolanle, and Tomi, (2012) reported that 19% of the trainee teacher taught that SCD is caused by evil spirit. In the same study, it was reported that 27% of the respondents thought SCD can be caused by bad food (Cornelius et al., 2012).

2.4 Perception of respondents on preventing sickle cell disease

Individuals living with SCD face several challenges that negatively affect their productivity. The problem of the person living with sickle cell disease goes beyond grappling with the overwhelming health effects of the disease. The people are also often stigmatized and discriminated; this often forces families to hide their sick (Tusuubira, Nakayinga, Mwambi, Odda, Kiconco and Komuhangi, 2018). Despite the relatively high level of knowledge, about one third of the participants were still reluctant to carry out premarital testing. Such attitude calls for immediate need for community-based campaigns to encourage the public to do regular premarital testing for intending couples (Omar, Yahya, Ishita, Allal, Khalil and Samir, 2014).

2.5 Conceptual framework

Health Belief Model

The Health Belief Model was used to investigate the Knowledge and Perception of out-of-School youths on SCD. This framework views people's beliefs about whether or not they are susceptible to a disease, and their perceptions of the benefits of trying to avoid it, influenced their readiness to act. The health belief model consists of six main conditions which are:

- > Believe they are susceptible to the condition (perceived susceptibility)
- ➤ Believe the condition has serious consequences (perceived severity)
- ➤ Believe taking action would reduce their susceptibility to the condition or its severity (perceived benefits)
- > Believe costs of taking action (perceived barriers) are outweighed by the benefits
- Are exposed to factors that prompt action (e.g., a television ad, seeing a friend or relative with Sickle cell disease having crises, and information of the death of a neighbor who suffered from SCD) (cue to action)
- Are confident in their ability to successfully perform an action (self-efficacy)

PREVENTION OF SICKLE CELL DISEASE - GENETIC COUNSELING

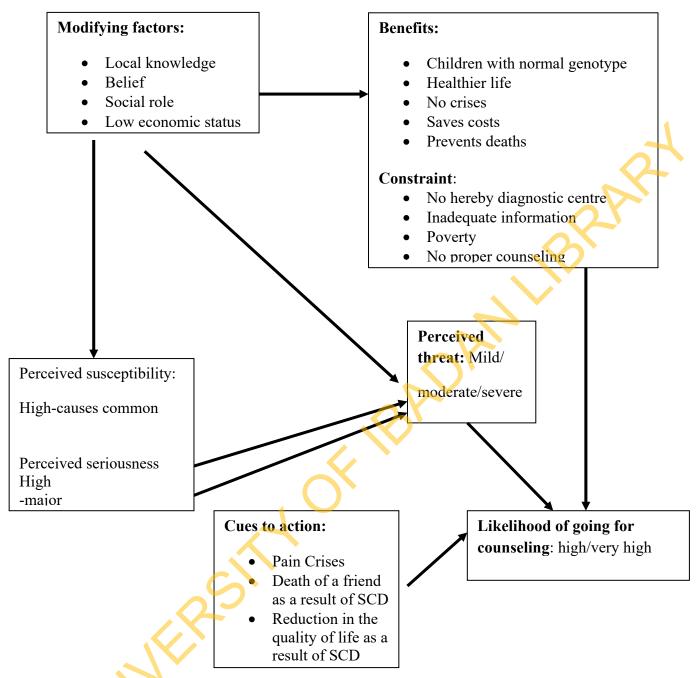


Fig. 2.6: Health Belief Model

CHAPTER THREE

METHODOLOGY

3.1 Study design

The study was a descriptive cross-sectional survey. Data were collected between September and October 2018 using an interviewer-administered questionnaire which had 49-item that elicited information on the respondents' socio-demographic characteristics, knowledge of sickle cell disease and their perception about the disease in Ibadan North East Local Government Area of Oyo State.

3.2 Study area

The study was carried out in communities within Ibadan North East Local Government Area in Oyo State. Ibadan North East Local Government area is situated in Oyo state, southwest geopolitical zone of Nigeria. The local Government has its administrative headquarter located along the Iwo Road axis of Ibadan, a major entry point through, Ife/Ibadan express way end of the Oyo State capital.

Oyo State is one of the thirty six states in Nigeria and it is located in the South Western region of the country. The state was created in 1976 out of the old Western region and has a projected population of about eight million (Nigerian Population Commission, 2016). Ibadan North East Local Government Area was carved out of the defunct Ibadan Municipal Government and derived its name from the metropolitan nature of the area. It is an urban area and occupies a total area of 18 square Kilometers and an average temperature of 28 degrees centigrade. The average humidity level of the area is 61 percent while the total annual precipitation of the Local Government is 2100mm of rainfall.

The inhabitants of the local Government are predominantly Yoruba, although it is highly heterogeneous, accommodating people from various other tribes who either engage in commercial activities or work in the public service. The 2016 estimated population for the area was projected 7,840900 people, using a growth rate of 3.2% from 2006 census. The Local Government shares boundaries with Egbeda, Ona-Ara, Ibadan North, Lagelu, Akinyele, and Ibadan South East Local Government.

3.3 Study population

The survey considered a sample size of 330 respondents which was obtained using the formula by Kish and Leslie (1965) for cross-sectional studies at a 5% level of significance, though the response rate for this study was 93%. The population prevalence for youths (73.4%; Durotoye, Salaudeen, Babatunde, Bosah and Ajayi, 2013) was used in the calculation of the sample size, a non-response rate of 10% of the sample size was added and a total of 330 respondents were gotten. The population studied was out-of-school youths male and female aged 15-24 (WHO, 2006), who have not been in school for at least an academic session.

Inclusion criteria

• Any youth male and female aged 15-24 years that is currently out of school, living in Ibadan North East local government area of Oyo State.

Exclusion criteria

 Youths who are presently in School or have been out-of-school for less than an academic session.

3.4 Sample size determination

The sample size for this study was estimated from the Leslie Kish formula (1965) for single proportion which is as follows:

- $N = \underline{Z^2pq}$ d^2
- N=minimum sample size
- Z= standard normal deviation set at 1.96 normal interval
- Q=proportion that does not have the characteristics being investigated (q = 1-p)
- P= The population prevalence for youths (73.4%; Durotoye, Salaudeen, Babatunde, Bosah and Ajayi, 2013).
- d=degree of accuracy set at 5% level of significance

Therefore, the sample size $N = (1.96)^2 \times 0.734 \times 0.266 / 0.05^2$

$$N=300.019$$

A non-response rate of 10% of 300 which equals 30

Therefore 30 will be added to the sample size calculated to make the Sample size 330 in order to address the issues of incomplete response.

3.5 Sampling Technique

The survey considered a sample size of 330 respondents which was obtained using the formula by Kish and Leslie (1965) for cross-sectional studies and a 95% confidence level. The population prevalence for youths (73.4%; Durotoye, Salaudeen, Babatunde, Bosah and Ajayi, 2013) was used in the calculation of the sample size, a non-response rate of 10% of the sample size was added and a total of 330 respondents were gotten. The response rate was 93%. Ibadan North East Local government area has twelve (12) wards, the twelve wards were divided into five main clusters, and three out of the five clusters were selected for the study using simple random sampling by balloting. Convenient sampling was used to select the respondents such that all persons who met the inclusion criteria during each visit to the communities were included in the survey. Eligible participants were male and female out-of-school youths, between the ages of 15-24years who must not have been in the classroom for a minimum of one academic session and also lived in these selected communities.

4. Method of data collection

The tool for data collection was a pre-tested, semi-structured interviewer-administered questionnaire, with four sections A-D.

Information found in the questionnaire included: Section A, socio-demographic characteristics, section B, knowledge about SCD including misconceptions and causes of SCD, section C, perception of Out-of-school youths on sickle cell disease and section D perception about preventing SCD.

1. The instrument for data collection was an interviewer-administered questionnaire which included a 49-item, was used to elicit information on the respondents' socio-demographic characteristics, knowledge of sickle cell disease and perception. The total knowledge score was 11. Knowledge scores 0-5, >5-8, and >8 were categorized as poor, fair, and good knowledge respectively. The total perception score was 20. Perception scores 0-5, >5-10, and >10 were categorized as negative, lukewarm, and positive perception respectively.

Validity of the instrument

2. Proper literature review was done and the instrument was designed based on the study objectives. To ensure face and content validity, the administered questionnaire

(instrument) was translated and back translated; it was also given to my supervisor and other experts in the field of public health for review and correction. Before the commencement of the study, the instrument was subjected to a pretest among out-of-school youths in Ibadan North Local Government. The population in the pre-test had a similar characteristic with the main target population.

3. Reliability of instrument

To ensure reliability, the questionnaire was pretested among 30 out-of-school youths (10% of the total study population at Ibadan North Local Government, this local government, shares a similar characteristic with the study area). The data was then subjected to Cronbach's Alpha statistical test. A result showing a Cronbach's Alpha value of 0.8 was gotten. This was accepted as reliable because it is close to 1.

3.6. Data management and analysis

This was done by collating the retrieved questionnaires and reviewing them to ensure consistency and completeness. Serial numbers were written on the questionnaire for correct data entry and analysis. A coding guide was developed for entering each question into the computer after a careful review of the responses and appropriate scores were allotted to each question. Cleaning, sorting and coding of data for analysis were properly done. Chi-square and Fishers exact test at 0.5% level of significance were conducted to assess significant associations between the dependent and independent variables. Results were presented in prose, tables, charts and percentages.

Respondents' knowledge of sickle cell disease was measured on an 11-point knowledge scale. Correct response for each statement was scored one (1) while the wrong response was scored zero (0), the total knowledge score was 11. Knowledge scores 0-5, >5, and >8 were categorized as poor, fair, and good knowledge respectively.

Respondents' perception on sickle cell disease was calculated on a 20-point perception scale. The total perception score was 20. Perception scores 0-5, >5-10, and >10 were categorized as negative, lukewarm, and positive perception respectively.

3.7. Ethical consideration

Approval to carry out the study was sought and gotten from Oyo State Ministry of Health Ibadan. Serial numbers were used on the administered questionnaire instead of names. Informed consent was sought and obtained from the participants, after careful explanation of purpose of the study, risks, benefits and that they can discontinue participation in the study at any point, if they wished was known to the respondent

CHAPTER FOUR

RESULTS

This section contains findings on respondents' awareness about SCD, their knowledge about the disease and sources of information. It also discussed the awareness of respondents on Sickle Cell Trait (SCT). Respondents' knowledge about personal blood genotype and highlights on the reasons given by individuals who have never done a blood genotype test on why they have never done the test. Likewise, the perception of respondents on SCD is reported.

The response rate for this study was 93%. A total of 307 out-of-school youths took part in the study. They comprised (58.6%) male, (41.4%) female, with male to female ratio of 1.4:1. The ages of the participants ranged between 15-24years with mean age of 20.8±2.2 years. More than half (50.8%), of the respondents are Christians, (47.9%) of the respondents are of the Muslim faith. Majority of the participants about (72.6%) belonged to Yoruba ethnic group, (10.1%) Hausa, (3.6%) Igbo and (13.4%) are from Fulani ethnic group. From the data collected on their marital status, it was discovered that (47.2%) of the respondents were married, a higher percent (52.4%) of the participants belonged to the category of people who were not married or single (Table 4.1a).

It is deduced that quite a number of the respondents (50.8%) had completed Secondary school, though majority of the respondents who claimed to have completed secondary school were basic skill deficient for they couldn't read and write, (20.5%) have attended secondary school but couldn't complete their education in order to acquire the Senior School Leaving Certificate, but dropped out along the way, most of the respondents who dropped out, left before writing the Junior School Leaving Certificate examinations. A number of the respondents, (18.6%) completed Primary school but couldn't go to secondary school and (8.1%) have never attended school or had access to any form of formal or informal education, and (2.0%) of the respondents have been exposed to learning how to read the Quran (Table 4.1a).

Table 4.1b presents the distribution of the respondents by their occupation. Traders (29.6%) topped the list; followed by tailors (20.2%) while 10.1% were Hairdressers/Barber, Drivers

accounted for 8.5% of the respondents. Entrepreneurs accounted for 7.8% of the respondents. Farmers comprised 2.6% of the respondents. Less than ten percent of the study participants 7.5% belonged to the group categorized as others like gatekeeper, house helps, bricklayer, bar

Table 4.1a: Socio-demographic characteristics of respondents (N=307)

Variable	No	(%)
Sex		
Male	180	58.6
Female	127	41.4
Age group		
15-18	76	24.8
19-21	83	27.0
22-24	148	48.2
Religion		(%)
Christianity	156	50.8
Islam	147	47.9
Traditional religion	3	1.0
Others	1	0.3
Marital status		
Married	145)	47.2
Single	161	52.4
Divorced	1	0.3
Level of education		
Never attended school	25	8.1
Primary	57	18.6
Some secondary	63	20.5
Secondary	156	50.8
Quranic education	6	2.0
Ethnicity		
Yoruba	223	72.6
Hausa	31	10.1
Igbo	11	3.6
Fulani	41	13.4
Others	1	0.3

Mean=20.8±2.

Table 4.1b: Distribution of Respondents' Occupation (N=307)

Occupation	Frequency	Percent (%)
Trading	91	29.6
Tailoring	62	20.2
Hairdressing/Barbing	31	10.1
Driving	26	8.5
Entrepreneur	24	7.8
Welding	17	5.5
Auxiliary Nurse	11	3.6
Mechanic	11	3.6
Vulcanizing	2	0.7
Farming	8	2.6
Others*	23	7.5
None	H	0.3

^{*}Others; these are respondents that are into jobs like gatekeeper, house help, cobbler etc.

4.1: Respondents' Knowledge of Sickle Cell Disease and Sickle Cell Trait

Respondents' awareness and sources of information on SCD is presented in Table 4.2. The vast majority (94.8%) of the respondents have heard about SCD. They got information about this disease from different sources. Respondents' sources of information is; friends (24.7%), family (25.4%), Relative (4.5%), Health Professionals (14.8%), School (12.0%), and mass media (18.6%) of the respondents. In the same table, it is revealed that (11.1%) of the respondents interviewed have heard about SCT. Furthermore the difference between SCD and SCT was asked to ascertain if they really knew about SCT. The question was correctly answered by twenty three respondents out of the thirty four respondents who claimed to have heard about SCT, which is (67.6%) of the total population of the respondents that have heard about SCT (Table 4.2).

Table 4.3 reveals the respondents who have heard about SCT, less than half (40.4%) of the respondents have heard about SCT. Amongst the respondents who have done a blood genotype test to determine their SCD status, several of them, (68.5%) were those who had the normal hemoglobin genotype AA, those who had the SCT genotype were (22.6%) of the respondents, the others had the abnormal hemoglobin genotype AC (4.8%), CC (1.6%), and SC (2.4%) of the respondents, but none of the respondents belonged to the blood genotype SS which is a more severe form of the disease (Table 4.4).

Majority of the respondents (64.5%) went for the genotype test as a result of health information gotten in different sources. Almost fifteen percent of the respondents (14.5%) went for the test because it was requested for during school admission, (9.7%) of the respondents went for the test as a result of clinical suspicion, (8.1%) of the respondents did the test because it was compulsory before marriage, (1.6%) had other reasons for during the test which was not listed in the options above (Table 4.5).

Respondents who had not done their blood genotype test gave reasons for not doing it, reasons given included; they never knew about blood genotype test (33.9%) of the respondents, (22.4%) claimed they don't know where to do the test, (3.3%) of the respondents said they do not have the money to do the test, (29.5%) of the respondents didn't have time to go for the test and (10.9%) of the respondents claimed they don't need the test, so it wasn't necessary to do it (Table 4.6). Respondents' readiness to go for a blood genotype test is presented in Table 4.7, out

of the one hundred and eighty three (183) participants who have not done the blood genotype test, almost all (154) are ready to go and do the test if there is an opportunity to do so, just a few, 29 of the respondents were not interested in going for the test because of the fear of the outcome of the test result.

More than half of the study participants (62.2%) could recognize a SCD patient with some physical features (Table 4.8). Less than ten percent (7.2%) of the respondents correctly knew how we can confirm the presence of SCD/SCT in an individual, majority (57.7%) felt that we can correctly confirm the presence of SCD with physical appearance, running nose (3.6%), high body temperature (2.3%) and (28.9%) of the respondents were not sure of how the presence of SCD is been confirmed in an individual (Table 4.9). Table 4.10 shows the family history on SCD, only (12.7%) of the respondents had a close relative who had SCD. The relationship of the respondent to those who had the disease in the family is; sister (28.2%), brother (23.1%), uncle (10.3%), aunt (12.8%), and grandparents (5.2%).

Table 4.11 represents respondents' knowledge on how SCD is acquired. This was correctly answered by less than fifty percent (42.6%) of the respondents. Some of the respondents (36.1%) did not have a knowledge or know how SCD is acquired, a number of the respondents (8.6%) said it can be contracted through body contact, exposure to hot sun (3.8%) of the respondents, mosquito bites (3.4), harsh weather (3.1%), sexual intercourse (1.7), and just two respondents (0.7%) claimed it could be acquired through sharing of sharp objects like blades, clippers etc.

Majority of the respondents (61.2%) had a good knowledge on the signs and symptoms of SCD (Table 4.12). Many of the respondents (65.6%) correctly knew the physical features of an individual with SCD (Table 4.13). Table 4.14 shows the knowledge of respondents on conception. Half (51.9%) of the respondents said a woman who has SCD cannot conceive and less than half (48.1%) of the respondents knew that SCD does not prevent conception. Respondents' knowledge on the causes of SCD and its diagnosis is found in Table 4.15, (33.3%) respondents believed that SCD can be caused by evil spirit, (66.7%) of the respondents knew that SCD cannot be caused by evil spirit. A vast majority (58.4%) of the respondents were not sure of how SCD is been diagnosed, (4.5%) of the respondents though SCD can be diagnosed through

malaria test, (0.3%) felt it could be diagnosed during ultrasound test. Less than half (36.8) of the respondents correctly knew how SCD is diagnosed (Table 4.15).

The knowledge of the respondents on the genotype of children born to parents who have SCD is represented in Table 4.16. No more than (32.6%) of the respondents knew that whenever both parents have SCD, they can never have offspring with a normal blood genotype. Some, (16.5%) of the respondents did not know what the genotype of the children whose parents have SCD will be. A number, (3.1%)of the respondents said parents with SCD have a quarter chance of having a healthy baby. Almost half of the respondents (45.4%) claimed parents with SCD have a half chance of having a healthy baby, and just (2.4%) of the respondents said parents with SCD can have children who do not have SCD.

About the medications used by individuals to relief pain and the efficacy of the medicine; majority (49.8%) of the respondents believed the use of orthodox and conventional medicine been more effective. Some (4.8%) said prayer can help in relieving the pains, (12.7%) said the perfect medicine to relief pain during pain crises in SCD patients is herbal medicine. Some, (13.7%) of the respondents did not have an idea of what can be used to relief pain in SCD patients (Table 4.17).

Table 4.2: Respondents' awareness and sources of information on SCD and SCT

Statement	No.	(%)
Ever heard about SCD (n=307)		
Yes	291	94.8
No	16	5.2
Sources of information (n=291)		DA.
Friends	72	24.7
Family	74	25.4
Relative	13	4.5
Health Professionals	43	14.8
School	35	12.0
Mass media	54	18.6
Ever heard about SCT (n=307)		
Yes	34	11.1
No	273	88.9
Any difference between SCD and SCT (n=34)		
Yes*	23	67.6
No	11	32.4

^{*}Correct response

Table 4.3: Respondents' knowledge about personal blood genotype (N=307)

No.	(%)
124	40.4
183	59.6
307	100
	IBK
DAI	
Br	
	183

Table 4.4: Respondents' blood genotype distribution (N=124)

	No.	(%)
AA	85	68.5
AS	28	22.6
AC	6	4.8
CC	2	1.6
SC	3	2.4

Table 4.5: Respondents' reason for doing the blood genotype test (N=124)

	No.	(%)
As a result of health information	82	66.1
Request as a result of school admission	18	14.5
Clinical suspicion	12	9.7
Pre-requisite for marriage	10	8.1
Others reasons	2	1.6
JANIVERSIN		

Table 4.6: Reasons for not doing personal blood genotype (N=183)

	No.	(%)
Don't know about it	62	33.9
Have not gotten time to do it	54	29.5
Have not gotten where to do the test	41	22.4
Have not gotten money to do it	20	10.9
I don't need it	6.0	3.3
25/14		

Table 4.7: Respondents' readiness to do blood genotype test (N=183)

Readiness to do blood genotype test	No.	(%)
Yes	154	84.2
No	29	15.8
Total	183	100.0
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JAINE.		

Table 4.8: Respondents' ability to identify an individual with SCD (N=291)

Can you identify an individual with SCD	No.	(%)
Yes	181	62.2
No	110	37.8
Total	291	100
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25		

Table 4.9: Respondents' knowledge on confirming SCD in an individual (N=291)

Physical appearance 168 57.7 Not sure 84 28.9 Conducting a blood genotype test* 21 7.2 Running nose 11 3.8 High body temperature 7 2.4 *Correct response	Not sure 84 28.9 Conducting a blood genotype test* 21 7.2 Running nose 11 3.8 High body temperature 7 2.4	Confirming that an individual has SCD?	No.	(%)
Conducting a blood genotype test* 21 7.2 Running nose 11 3.8 High body temperature 7 2.4 *Correct response	Conducting a blood genotype test* 21 7.2 Running nose 11 3.8 High body temperature 7 2.4 *Correct response	Physical appearance	168	57.7
Running nose 11 3.8 High body temperature 7 2.4 *Correct response	Running nose 11 3.8 High body temperature 7 2.4 *Correct response	Not sure	84	28.9
*Correct response	*Correct response	Conducting a blood genotype test*	21	7.2
*Correct response	*Correct response	Running nose	11	3.8
PSIN OF IBADA	PSITA OF IBADAR	High body temperature	7	2.4
AINTER SILVE	JANVERSILA		DAIR	
			5 Y	

Table 4.10: Respondents' family history of Sickle Cell Disease

Family history	No.	(%)
Anyone in the family having SCD? (n=307)		
Yes	39	12.7
No	268	87.3
Total	307	100
Relationship with the person (n=39)		
Sister	11	28.2
Brother	9	23.1
Uncle	4	10.3
Aunt	5	12.8
Grandmother	1	2.6
Grandfather	1	2.6
Others	8	20.5

Table 4.11: Respondents' knowledge about how SCD is acquired (N=307)

How SCD is acquired;	No.	(%)
Genetic transfer*	124	42.6
Don't know	105	36.1
Body contact	25	8.6
Exposure to hot sun	11	3.8
Mosquito bites	10	3.4
Harsh weather	9	3.1
Sexual intercourse	5	1.7
Sharing of sharps	2	0.7
*Correct response	S	

Table 4.12: Respondents' knowledge on the signs and symptoms of SCD (N=291)

Signs and symptoms of SCD	No.	(%)
Bone pain	3	1.0
Yellow coloration of the eyes and limbs	29	10.0
Body weight/height below normal for age	6	2.1
All of the above*	178	61.2
None of the above	75	25.8
*Best option	OP	
	0	
, 0		
SIN		
I.R.S.I.A.		
WERSHA O		

Table 4.13: Respondents' knowledge on the physical features of an individual with SCD (N=291)

Individuals with SCD are sometimes	No.	(%)
Shorter than their peers	11	3.8
Get tired easily	13	4.5
Mature later compared to their peers	2	0.7
All of the above*	191	65.6
None of the above	6	2.1
Not sure	68	23.4
SINO		
JER		

Table 4.14: Respondents' knowledge about conception with SCD (N=291)

51.9 48.1 100
48.1
48.1
100

Table 4.15: Knowledge of respondents' on causes of SCD and diagnosis (N=291)

Cause of SCD	No.	(%)
SCD can be caused by evil spirit		
True	97	33.3
False	194	66.7
How is SCD diagnosed		
Through blood genotype testing*	107	36.8
Through Conducting malaria parasite test	13)	4.5
Through Conducting ultrasound test	1	0.3
Not sure	190	58.4
*Correct response		

Table 4.16: Respondents' knowledge on the genotype of children whose parents have SCT/SCD

Chances of getting a healthy/normal child when both paren	nts have SCD	2
	No.	(%)
None of the children*	95	32.6
All of the children	7	2.4
Half chance of getting a healthy baby	132	45.4
Quarter chance baby will be normal	9	3.1
Don't know	48	16.5

^{*}Correct response

Table 4.17: Respondents' knowledge on medications used to relief pain in SCD persons (n=291)

Medication used by individuals to relief pain	No.	(%)
Herbal medicine	37	12.7
Conventional medicine*	55	18.8
Prayers	14	4.8
Use of herbs and conventional medicine	145	49.8
Don't know	40	13.7

^{*}Correct response.

Conventional medicines: Analgesic medicine and folic acid.

Figure 4.1 represents the knowledge score of respondents represented on a bar chart. The knowledge score of each respondent was calculated and categorized into three sections which is: good knowledge; fair knowledge; and poor knowledge about SCD. The knowledge score was categorized using a knowledge scale of 0-5 as poor knowledge; >5-8 as fair knowledge and knowledge score >8 as good knowledge about SCD. Making use of the knowledge scale prepared, just 11.4% of the respondents had good knowledge about SCD, but a few above half 50.5% of the respondents had fair knowledge about the disease and 38.1% of the respondents had a poor knowledge about the disease.

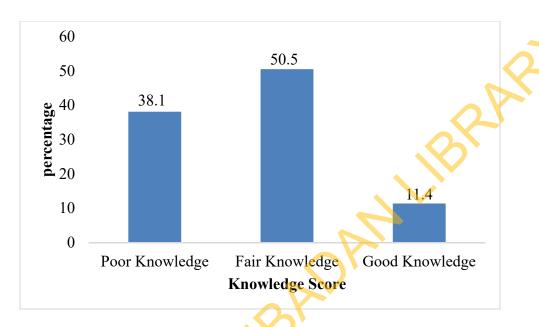


Figure 4.1: Levels of knowledge among respondents on Sickle cell disease.

4.2: The perception of respondents on Sickle Cell Disease

Table 4.18 highlights the perception of the respondents on Sickle Cell Disease. More than half 54.7% of the respondent agreed that anybody can have SCD irrespective of their race, gender, or marital status. Few of the respondents 21.5% were undecided about the presence of SCD been determined by race, color or other socio-demographic characteristics while 23.8% of the respondents disagreed to the above. More than a quarter of the respondents 33.6% had a wrong perception that they cannot have SCD/SCT even if they have never done the blood genotype test to confirm. Also 32.9% of the respondents said 'they cannot have SCD/SCT in our family'. Participants 32.6% agreed to a change in human genotype with age which is a wrong perception about SCD. Nearly half of the respondents had a perception that SCD is curable.

Likewise Table 4.18 presents the perceived causes of SCD. Almost forty percent 38.8% of the respondents had a perception that SCD is a form of spiritual attack. Some of them almost a quarter of the respondents feel SCD is caused as a result of walking too much under the sun during pregnancy precisely 20.8% of the respondents perceive SCD is also caused as a result of walking too much under the sun during pregnancy.

Furthermore the perceived severity of SCD is represented on this table, 16.6% of the respondents had a wrong perception that SCD is not a big deal, but it is only overemphasized by most health professionals. Almost half 41.4% of the respondent had a wrong perception that SCD does not affect an individual's productivity or ability to work. Respondents' perception about marriage was scrutinized, 86.0% accepted that knowing their SCD status can influence their decision to marry. Less than thirty percent 22.1% of the respondents agreed to getting married to an individual with SCD. Almost a quarter 22.5% of the respondents had a wrong perception of not caring about marrying a person with SCD/SCT even if they have SCD/SCT.

Perception about preventing SCD is represented in Table 4.19. Several of the respondents 62.2% had a perception that SCD can be prevented by offering prayers for protection. A large number 82.7% of the respondents had a good perception on screening newborn babies after birth to

reduce the prevalence of the disease. Also almost all 77.5% of the respondents had a good perception on marrying a spouse who is genetically compatible.

The relationship between respondents' socio-demographic characteristics and knowledge of Sickle Cell Disease is presented in Table 4.20. Greater part of the respondents 50.5% of the respondents had fair knowledge about SCD. A number of the respondents 38.11% had poor knowledge and only 11.4% of the respondents had good knowledge about SCD. Majorly 17.3% of the respondents within the age group of 22-24years had a poor knowledge about SCD, 11.4% of the respondents within the age group of 19-21 had poor knowledge about SCD and 9.4% of the respondents had poor knowledge about SCD.

A quarter 25.2% of the respondents within the age range of 19-21 had fear knowledge about SCD, likewise 21.9% of the respondents within the age range of 15-18years had fear knowledge about SCD. A higher percentage 68.6% of the male respondents had a good knowledge about SCD while a fewer percent 31.4% of the female respondents had good knowledge about SCD. 58.1% of the male respondents had fair knowledge about SCD whereas 41.9% of the female respondents had fair knowledge about the disease. 43.6% of the female respondents had a poor knowledge about SCD while 56.41% of the male respondents had a poor knowledge about SCD.

In addition, Table 4.20 shows that more respondents 77.1% of the Yoruba respondents had a good knowledge about SCD compared to Hausa and Igbo respondents who had a percentage of 2.9% good knowledge and Fulanis that had 17.1% good knowledge about SCD. Overall there was no statistically significant relationship between the age of the respondents, gender, religion, occupation, ethnicity, marital status, level of education and their knowledge about sickle cell disease.

Table 4.21 presents the relationship between respondents' socio-demographic characteristics and their perception about SCD. A large number, 73% of the respondents had an unfavorable perception about SCD. Just 27% of the respondents had a favorable perception about the disease.

Table 4.18: Respondents' perception on Sickle Cell Disease (N=307)

Statement	Agree (%)	Undecided (%)	Disagree (%)
Anybody can carry the sickle cell gene	168(54.7)*	66(21.5)	73(23.8)
I can never have SCD/SCT even if I've not done blood genotype test to confirm	103(33.6)	61(19.9)	143(46.6)*
We can never have SCD/SCT in our family	101(32.9)	65(21.2)	141(45.9)*
Human Genotype can change with age	100(32.6)	55(17.9)	152(49.5)*
SCD is curable	139(45.3)	49(16.0)	119(38.8)*
SCD affects an individual's productivity negatively	252(82.1)*	26(8.5)	29(9.4)
Perceived causes of SCD	Y		
SCD is a form of spiritual attack from the enemy	119(38.8)	41(13.4)	147(47.9)*
SCD is caused as a result of walking too much under the Sun during pregnancy	65(21.2)	49(16.0))	193(62.9)*
SCD is caused as a result of some foods eaten during the pregnancy of a baby	64(20.8)	51(16.6)	192(62.5)*
Perceived Severity of SCD			
SCD is not a big deal, it is only overemphasized	51(16.6)	31(10.1)	225(73.3)*
SCD does not affect an individual's ability to work or do rigorous activities	127(41.4)	23(7.5)	157(51.1)*
Perception about marriage			
Knowing my SCD status can influence my decision to marry	264(86.0)*	16(5.2)	27(8.8)
I can marry someone with SCD even, if I have SCD/SCT	68(22.1)	14(4.6)	225(73.3)*
As an individual with SCT/SCD I don't mind marrying someone with SCD/SCD	69(22.5)	9(2.9)	229(74.6)*

*Good perception.

4.3 Respondents' perception on preventing Sickle Cell Disease

Table 4.19 represents the perception of respondents on preventing SCD. A high number of the respondents 62.2% had a perception that SCD can be healed by prayer. Almost all the respondents 82.7% agreed to the fact that counseling and screening before marriage can help to the prevention of the disease. Almost half 45.6% of the respondents had a perception that a regular intake of some herbs can help in preventing the occurrence of the disease. A vast majority of the respondents 64.8% agreed that screening of new born babies can help in preventing the disease. A good number of the respondents 41.7% had a perception that taking an adequate diet can help in preventing the occurrence of SCD.

Table 4.19: Respondents' perception on preventing Sickle Cell Disease

Perception on preventing sickle cell disease	True (%)	False (%)	Not sure (%)
SCD is prevented by offering prayers of protection	191(62.2)	84(27.4)*	32(10.4)
against the disease and healing for affected			2
individuals			
Genetic transfer of SCD can be prevented by	254(82.7)*	15(4.9)	38(12.4)
counseling and testing before marriage	7		
SCD can be prevented by the use of herbs	140(45.6)	94(30.6)*	73(23.8)
The prevalence of SCD can be reduced by screening	199(64.8)*	30(9.8)	78(25.4)
newborn babies for the disease	•		
SCD can be prevented by eating good food	128(41.7)	121(39.4)*	58(18.9)
SCD can be prevented by marrying a spouse who is	238(77.5)*	22(7.2)	47(15.3)
genetically compatible			
*Positive perception			

4.4 Test of hypotheses

In other to have a clear view of the association between variables, Chi-square Test was used set at p-value<0.05 to ascertain the true association of all the variables being considered in the sociodemographic status of the respondents and their knowledge and perception on SCD.

Ho I: There is no significant difference between the socio-demographic characteristics of the respondents and their knowledge about sickle cell disease.

Chi-square test statistics was used to measure the association between the socio-demographic characteristics of the respondents and their knowledge. Result showed $X^2=29.375^a$, P (>0.05), therefore, the association was not significant and the hypothesis accepted. Bulk 34(11.1%) of the respondents within the age range of 15-18 years had fair knowledge, compared to 35(11.4%) of the respondents between the ages 19-21 years who had poor knowledge (Table 4.20).

Ho II: There is no significant difference between the gender of respondents and their perception about SCD.

Chi-square test statistics was used to measure the association between the socio-demographic characteristics of the respondents and their perception about SCD. Result showed $X^2=14.300^a$, df=2, P (<0.001) between the gender and socio-demographic characteristics, therefore, the association was significant and the hypothesis rejected. Majority of the male 78.9% of the respondents had a positive perception on SCD compared to 64.6% of the female respondents. More of the female respondents 35.4% had lukewarm perception about SCD compared to 21.1% of the male respondents who had negative perception (Table 4.7).

Table 4.20: Relationship between respondent' socio-demographic characteristics and their knowledge scores on SCD (N=307). *Represents values for Fisher's exact

Socio-demographic characteristics	Knowledge about sickle cell disease (SCD)						
	Poor No(%)	Fair No(%)	Good No(%)	Total	df	X ²	P-value
Age group (years)					X		
15-18	29(9.4)	34(11.1)	13(4.2)	76(24.8)	4	5.053	0.282
19-21	35(11.4)	39(12.7)	9(2.9)	83(27.0)			
22-24	53(17.3)	82(26.7)	13(4.2)	148(48.2)			
Gender							
Male	66(21.5)	90(29.3)	24(7.8)	180(58.6)	4	1.684	0.431
Female	51(16.6)	65(21.2)	11(3.6)	127(41.4)			
Religion							
Christianity	50(16.3)	89(29.0)	17(5.5)	156(50.8)	6	9.498*	0.089
Islam	65(21.2)	65(21.2)	17(5.5)	147(47.9)			
Traditional religion	1(0.3)	1(0.3)	1(0.3)	3(1.0)			
Others	1(0.3)	0(0.0)	1(0.3)	1(0.3)			
Ethnicity	o `						
Yoruba	84(27.4)	112(36.5)	27(8.8)	223(72.6)	8	6.559*	0.598
Hausa	10(3.3)	20(6.5)	1(0.3)	31(10.1)			
Igbo	5(1.6)	5(1.6)	1(0.3)	11(3.6)			
Fulani	17(5.5)	18(5.9)	6(2.0)	41(13.4)			
Others	1(0.3)	0(0.0)	0(0.0)	1(0.3)			
Level of education							
Never attended school	12(3.9)	10(3.3)	3(1.0)	25(8.1)	8	7.523*	0.457
Primary	23(7.5)	30(9.8)	4(1.3)	57(18.6)			

Some secondary	28(9.1)	26(8.5)	9(2.9)	63(20.5)
Secondary	53(17.3)	84(27.4)	19(6.2)	156(50.8)

Table 4.21: Relationship between respondent' socio-demographic characteristics and their perception scores on SCD $\,$ (N=307)

Socio-demographic characteristics	Perception SCD	n of respon	ndents on	Total	df	Chi- square/F	P-value
	Negative No(%)	Lukewarm No(%)	Positive No(%)			isher exact	
Sex					0		
Male	11(3.6)	113(36.8)	56(18.2)	180	2	14.300	P=0.001
Female	13(4.2)	52(17.0)	62(20.2`)	127			
Age group (years)							
15-18	6(1.9)	38(12.4)	32(10.4)	76	4	0.980	0.913
19-21	6(1.9)	44(14.3)	33(10.8)	83			
22-24	12(3.9)	83(27.1)	53(17.3)	148			
Religion							
Christian	12(3.9)	78(25.4)	66(21.5)	156	8	5.096**	0.573
Islam	12(3.9)	85(27.7)	50(16.3)	147			
Traditional	0(0.0)	1(0.3)	2(0.7)	3			
Others	0(0.0)	1(0.3)	0(0.0)	1			
Level of education							
Never attended school	3(0.9)	10(3.3)	12(3.9)	25	8	3.985**	0.853
Primary	3(0.9)	34(11.1)	20(6.5)	57			
Some secondary	6(2.0)	33(10.8)	24(7.8)	63			
Secondary	12(3.9)	85(27.7)	59(19.2)	156			
Others	0(0.0)	3(1.0)	3(1.0.0)	6			

^{**}Fisher exact

CHAPTER FIVE

DISCUSSION, CONCLUSION AND RECOMMENDATIONS

5.1 Discussion

5.1.1 Socio-demographic profile of the respondents

The ages of the respondents ranged between 15-24 years with a mean age of 20.81±2.23 years. The majority of the respondents were between the ages 22-24 years. The results reveal that a reasonable proportion of the study population was made up of young adults. There were more males when compared to females among the respondents, this is comparable to the report of Olanrewaju et al., (2013) who had similar result but contrary to the report of Shaikha and Amani (2010); Olatona et al., (2012); Ezenwosu et al., (2015) who reported the respondents' been more of a female population than the males.

Greater part of the respondents were practicing the Christian and Islamic religion, just one percent of the respondents were practicing the traditional religion, less than one percent of the respondents were practicing other religion not listed in the options. More than half of the respondents were Christians. A study conducted by Olatona et al., (2012) had almost similar result in which majority of their respondents were Christians. Almost all the participants were working and were into different vocations with Traders topping the list with a percentage of 29.6%. Majority of the respondents' (72.6%) were understandably of the Yoruba ethnic group as the study was carried out in the South Western region of Nigeria majorly populated by this ethnic group. Half of the respondents 50.8% had completed secondary school; this result is similar to the findings of Hassan Awwalu, Okpetu and Waziri, (2017).

5.1.2 Awareness and knowledge about sickle cell disease

Findings from this study revealed that majority of the respondents have heard about SCD which may mean that they know of its existence. However, the fact that only a small proportion obtained such information from a health professional may suggest that there is limited effort in health care settings to inform the public of SCD. Friends and family is the main source of information. This is similar to a recent study reported by Tusuubira et al., (2018) carried out among adults in the community, in the study it was reported that the respondents had ever heard of SCD with the highest proportion of the respondents hearing of it from friends and family and this is also comparable to the report of Boadu and Addoah (2018).

Though many of the respondents have heard about the disease, only a few of the respondents have heard about SCT, this is in resonance with the report of Boadu and Addoah (2018) on the study conducted among undergraduates. Less than ten percent of the respondents knew the difference between SCD and SCT. This finding is at variance with the report of Ezenwosu et al., (2015) where they found that about ninety percent of the respondents were aware of their individual SCT status, the difference in the result might be because the study participants were parents of children with SCD and they might have been exposed to series of information regarding SCD Moronkola and Fadairo (2007)

Less than half of the respondents have done and knew their individual blood genotype, this is congruent to the findings of Owusu et al., (2018) in which he reported that sixty percent of the study participants had no knowledge on their status or family history. In accordance to Faremi et al., (2018) more of the respondents belonged to the blood genotype AA which is the normal human blood genotype. There were other respondents with blood genotype, AS, AC, CC, and SC. None of the respondents had the blood genotype SS, this is expected as human hemoglobin HbSS is a severe form of the disease and many of those who are carriers of such blood genotype are usually careful in doing activities that might stress them which in turn will precipitate pain episodes or crises.

Amongst the respondents who knew their blood genotype, a vast majority of the individuals went to test for their genotype as a result of health information. Other reasons for doing the blood genotype test was; as a result of school admission, some on the basis of clinical suspicion of a child which makes the health personnel test the parents and others said they did the blood genotype test because it was compulsory in their churches to bring a result of the test before they could get married to their spouses. Those who have not done a blood genotype test gave excuses for not been able to do the test. Some of the reasons were; they don't know about the blood genotype test, have not gotten a place to do the test, the funds and time to do the test was not

available and others felt it was not necessary to do the test as they were very sure that they can never have SCT/SCD in their bodies.

In this study it was discovered that very few of the respondents correctly knew which test was used to confirm the presence of SCD/SCT. Majority of the respondents didn't know how SCD is diagnosed; this result is in accordance to the study of Olanrewaju et al., (2013) who reported similar result. In his study it was reported that less than sixty percent of the respondents knew that the disease can only be diagnosed through blood test. Findings from my study reveal that respondents thought SCD could be diagnosed and confirmed with a physical examination of the body. Some thought it could be confirmed with the presence of a high temperature or a continual running nose. Findings from this showed that the respondents had close relatives who had SCD and more of those relatives were sisters of the respondents and brothers with other relatives been their uncles, aunties and grandparents. Some of the respondents said that SCD is caused by evil spirit, this is similar to the report of Olanrewaju et al., (2013) in his study more than one fourth had wrong belief that SCD is caused by evil spirit.

Findings from this study show that, generally knowledge of SCD was fair as half of the respondents had a fair knowledge about SCD. In the study about forty percent of the respondents had poor knowledge about SCD and very few of the respondents had good know about SCD. This result is similar to the report of Olatona et al., (2012), in the study titled Effects of Health Education on Knowledge and Attitude of Youth Corps Members to Sickle Cell Disease and its Screening in Lagos State. In his study quarter of the respondents had good knowledge about SCD. The knowledge categorization of respondents by age; it was expected that the younger age category would have a better knowledge of SCD but it was the contrary, there was no difference in the knowledge score of respondents within the age group 15-18 years and those within the age group 22-24years this is similar to the findings of Shaika and Amani (2009), on Public awareness of sickle cell disease in Bahrain.

5.1.3 Perception of respondents on sickle cell disease

Findings in this study revealed that less than fifty percent of the respondents correctly knew how SCD could be acquired. There were some myths and misconception about the disease as some of the respondents thought a woman with SCD could not get pregnant. A number of the respondents believed SCD was a sickness caused by evil spirits or that it is a form of spiritual attack from the

enemy. Amongst the respondents some believed that two parents with SCD can still give birth to children with normal blood genotype as long as they have faith and can pray for a normal child. This result is in correspondence with the report of Tusuubaru et al., (2018) in which it was reported that The highest proportion of the respondents did not know the chance of having a healthy baby when all the parents have SCD. Sickle cell disease was perceived by some of the respondents as not been a big deal but that it is just one of the diseases overemphasized by health professionals, because they believed that SCD was one of the childhood diseases and human genotype is meant to change with age, and that such disease will be overcome as the child grows into adulthood. Some of the misconceptions revealed in the study that; SCD is caused as a result of the food eaten during the pregnancy of a baby, and walking too much under the sun can be the main cause of SCD in a child.

5.1.4 Perception of respondents on preventing sickle cell disease

Generally it was found that majority of the respondents had a poor perception about preventing and reducing the prevalence and burden of the disease, just few of the respondents had a good preventive perception. In the study it was found that respondents agreed that eating healthy is a means of preventing the occurrence of SCD. Majority of the respondents agreed to routine testing of new born babies as a means of reducing the prevalence of the disease. Some of the respondents believed praying to God against the disease as a good means of reducing the number of children that will be born with the disease. Several of the respondents saw premarital counseling and testing as a good way of prevention that will help reduce the burden of the disease.

Majority of the respondents in my study agreed to the efficacy of prayer as a means of preventing and cure for SCD. This is in accordance to the study of Nnko, Bukenya, Kavishe, Biraro and Peck et al., (2015), on Public perceptions of terminologies, Aetiologies, symptoms and preferred management.

5.1.5 Implication for health promotion and education

Health education focuses on the modification of people's behaviour and behavioural factors for health, Green and Kreuter (1991). Health education can help in increasing knowledge and improving attitude of individuals on SCD, this is evidenced by a study conducted by Olatona et al., 2012, in his study there was an increase in knowledge of the respondents about SCD from a

quarter which was the baseline knowledge score to above sixty percent after health education. This study was conducted among Youth Corps in Lagos. Findings from my study have several implications for multiple health promotion and education interventions. The issues which health promotion and education particularly needs to address are; misconceptions and knowledge relating to sickle cell disease. Public enlightenment, training of community educators and counseling are key strategies which can be used to tackle the challenges identified in this study.

Public enlightenment programs involving mass communication, jingles, dramas, are useful in helping to create awareness and influence their knowledge and perception related to SCD. According to Adeyemo, the mass media can be used to raise people's awareness, upgrade their knowledge and modify their perception relating to health issues (Adeyemo 2015). Several radio and television stations can be a useful medium for disseminating information and increasing awareness on SCD in the community. Leaflet, pamphlets and posters are additional behavioral communication and public enlightenment tools that can be used. Public enlightenment messages should be targeted mainly to the community and out-of-school youths on the severity of the disease and its ability to cause morbidity and also early mortality in individuals. The messages for public enlightenment should specify and stress the need to prevent the occurrence of this disease because the cure is almost quite impossible in Nigeria because of the state of many of the health facilities.

Training is an educational strategy for upgrading peoples' knowledge and skill. The strategy can be used to upgrade the knowledge of out-of-school youths in the community on SCD as well as understanding the physiology of the disease, its mode of inheritance, ways of preventing the disease and ways to help individuals who have the disease live a healthier life. Teaching methods should involve youth friendly, interactive and participatory sessions, other methods for behavior change can include working in groups, role-playing, story-telling and participation in discussions that would centre on ways to eradicate misconceptions, improve favorable perception and increase knowledge on SCD.

A combination of two or more of the aforementioned health promotion and education strategies would be useful. This is due to the inherent advantages of the approach. Use of a combination of a strategy ensures that the weakness of one is counterbalanced by the strengths of the others.

5.2 Conclusion

The findings in this study showed a high level of general awareness about the reality of SCD but comprehensive knowledge about the cause and prevention of SCD was low and associated with vast misconceptions. Most of the respondents could not differentiate between SCD and SCT. Some of the respondents didn't know how SCD is acquired and how it can be diagnosed to confirm that an individual has SCD. Some of them believed the disease is not a big deal but it is only overemphasized by health professionals.

A large number of the respondents did not see its importance in influencing marital decisions. If sickle cell disease control strategies must yield any significant results, more education about SCD, especially among out-of-school youths in the community in Nigeria is therefore recommended. The use of persons with SCD as peer educators/counselors should be explored. Most of the respondents could not differentiate between SCD and SCT. Some respondents claimed the children of women will not have SCD if they were careful of what they are during pregnancy and if pregnant women avoid excessive sunlight; this perception can be changed with adequate health education.

5.3 Recommendations

In light of these findings the following recommendations were made:

- 1. Public enlightenment activities using audiovisuals, jingles and drama on Television and Radio which can easily be understood by a layman should be used to increase awareness and promote positive perception about the disease among out-of-school youths.
- 2. Peer education approach should be used to increase knowledge and reduce misconceptions about the disease.
- 3. Sensitization and workshop using the different associations to increase correct knowledge about the disease.
- 4. Use of religious leaders to ensure intending couples do counseling and testing for SCD before marriage.

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APPENDICES

APPENDIX I

KNOWLEDGE AND PERCEPTION OF OUT-OF-SCHOOL YOUTHS ON SICKLE CELL DISEASE IN IBADAN NORTH EAST LOCAL GOVERNMENT AREA, OYO STATE

INFORMED CONSENT

Dear Respondent,

My name is **GANSARI Beatrice Bona**, I am a Postgraduate student of the department of Health Promotion and Education, Faculty of Public Health, College of Medicine, University of Ibadan. The aim of this study is to investigate on the **Knowledge and Perception of Out-of-school Youths on Sickle Cell Disease in Ibadan North East Local Government Area, Oyo State.** There are no wrong or right answers to the questions asked or statements made, what is desired of you is your honest answer. Please note that the completion of the questionnaire is entirely voluntary. All information provided will be used in advancing knowledge and designing interventions that will help in reducing the prevalence of Sickle Cell Disease.

Thanks for your cooperation.

- You are free to refuse to take part in this programme. You are right to withdraw at any time if you choose to. I will greatly appreciate your help in responding to the survey and taking part in this study.
- Consent: Now that the study has been well explained to me and I fully understand the content of the process, I will be willing to take part in the programme.

APPENDIX II

QUESTIONNAIRE

KNOWLEDGE AND PERCEPTION OF OUT-OF-SCHOOL YOUTHS ON SICKLE CELL DISEASE IN IBADAN NORTH EAST LOCAL GOVERNMENT AREA, OYO STATE

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Socio-d	lemograp	hics
Socio d	icinosi ap	,,,,,

C10-	ucmographics
1.	Age as at last birthday (in years)
2.	Gender (1) Male[] (2) Female[]
3.	What is your Religion? (1)Christianity[] (2) Islam[] (3) Traditional[]
	(4) Others (Please Specify)
4.	Ethnic group: (1) Yoruba[] (2) Hausa[] (3) Igbo[] (4) Others (please specify)
5.	Marital Status: (1) Married[] (2) Never Married[] (3) Separated[] (4)Divorced[]
	(5) Widowed [] (6) Single[]
6.	Highest level of education obtained: (1) Never attended School [] (2) Primary School[]
	(3) Some Secondary [] (4) Secondary [] (5) Others (please specify)
7.	Occupation: (1) Tailoring[] (2) Welding[] (3) Driving[] (4)Hairdressing[]
	(5)Trading[] (6) None[]

SECTION B:

KNOWLEDGE OF OUT-OF-SCHOOL YOUTHS ON SICKLE CELL DISEASE

Please read and tick the appropriate answer below

- 8. Have you ever heard about sickle cell disease? 1. Yes [] 2. No []
 9. Where did you hear about it? 1. Friends [] 2. Family [] 3. Relative [] 4. Health professionals[] 5. School[] 6. Mass media[]
- 10. Have you heard about SCT? 1. Yes [] 2. No [] 3. Not sure[]

```
11. Is there any difference between SCD and SCT? 1. Yes[]
                                                             2. No[]
                                                                        3. Not sure [ ]
12. Have you ever done a blood genotype test? (If Yes answer question 13 and 14, if No,
skip to question 15 and 16). 1. Yes[]
                                           1. No[]
13. What is your blood genotype? 1. AA[] 2. AS[] 3. AC[]
                                                               4.CC[] 5. SC[]
14. Why did you do it? 1. Request as a result of school admission[] 2. Clinical suspicion[]
   3. As a result of health information[]
                                        4. A prerequisite for wedding[]
   5. Other reasons (please specify) -----
15. Why have you not done it? 1. Don't know about it[]
                                                         2. Have not gotten were to do it[]
   3. Have not gotten money to do it[]
                                         4. I don't need to do it[]
   5. Other reasons (please specify) ------
16. Would you like to conduct a blood genotype test if there is an opportunity to do it?
              2. No[] 3. Don't need it[]
17. Can you identify a person with sickle cell disease? 1. Yes[ ] 2.No[ ]
                                                                          3.Not sure[]
18. How can you confirm that an individual have SCD? 1. Conducting blood tests[]
    2. High body temperature [ ] 3. Running nose [ ] 4. Physical appearance [ ] 5. Not sure [ ]
19. Does anyone in your family have SCD? (If Yes, answer question 19b, if No skip question 1)
   1. Yes[]
              2. No[]
                              3. Not sure[]
19b. How is the person affected to you? \( \), Mother[ \] 2. Father[ \] 3. Sister[ \]
                                                                               4. Brother[]
                                                                         9. Others[]
    5. Uncle[] 6. Aunt[] 7. Grandmother[]
                                                    8. Grandfather[]
21. Sickle cell disease can be acquired through; 1. Body contact[]
                                                                 2. Harsh weather[]
                         4. Exposure to hot sun[] 5. Genetic transfer[]
   3. Mosquito bites[]
22. Signs and symptoms of SCD are:
   1. Bone pain[] 2. Yellow coloration of the eyes and limbs[] 3. Body weight/height below[]
normal for age [ ] 4. None of the above [ ] 5. All of the above [ ] 6. Not sure [ ]
23. Individuals with SCD may have: 1. An abnormal Sexual drive[ ] 2. Physical development
might be delayed [] 3. Males can have problems with ejaculation [] 4. All of the above []
5. None of the above [ ] 6. Not sure [ ]
24. Individuals with SCD are: 1. Sometimes shorter than their peers [ 2. Get tired very easily ]
   3. Mature later compared to their peers[] 4. All of the above[] 5. None of the above[]
6. Not sure [ ]
25. A woman with SCD cannot get pregnant: 1. True[]
                                                          2. False[]
                                                                        3. Not sure[]
26. SCD can be caused by evil spirits: 1. True[]
                                                      2. False[]
                                                                        3. Not sure []
```

27. How is SCD diagnosed? 1. Blood genotype test[] 2. Conducting malaria parasite test[]
3.Don't know[] 4. Not sure[]
28. Chance of getting a healthy baby when all the parents have SCD? 1. None of the children[]
2. All of the children[] 3. Half chance of getting a healthy baby[] 4. Quarter chanc
paby will be normal[] 5. Don't know[]
29. Medication for people with SCD: 1. Herbal medicine[] 2. Conventional medicine[]
3. Prayers[] 4. Don't know[]
30. Anybody can have the sickle cell gene: 1. True [] 2. False [] 3. Not sure []
31. Sickle cell disease can be prevented by marrying a spouse who is genetically compatible.
1 True [12 False [13 Not sure

SECTION C: PERCEPTION OF OUT-OF-SCHOOL YOUTHS TOWARDS SCD

S/N	STATEMENT	AGREE	UNDECIDED	DISAGREE
5/14	WITH ENVIENT		ONDECIDED	DISTIGNED
32	Anybody can carry the Sickle cell gene			
33	I can never have SCD, even if I have never			
	done blood genotype test to confirm			
34	We can never have SCD in our family			
35	SCD is a form of spiritual attack from the			
	enemy			
36	SCD is not a big deal, it is only			
	overemphasized			
27	EX			
37	Human genotype can change with age			
38	SCD is caused as a result of some foods eaten			
	during the pregnancy of a baby			
39	SCD is caused as a result of a woman			
	walking under the sun during pregnancy			
		1		

40	SCD is curable			
41	SCD affects an individual's productivity negatively			
42	Someone with SCD can work like a normal individual?			7
43	Exposure to harsh or extreme weather conditions can precipitate the occurrence of pain episodes in persons with the disease		.83	Alt
44	Knowing my SCD status can influence my decision to marry	•	7///	
45	I can marry someone with SCD			
46	As an individual with SCT/SCD I don't mind marrying someone with SCT/SCD			

Section D Perception about Prevention of Sickle Cell Disease

S/N	STATEMENT	TRUE	FALSE	NOT SURE
47	SCD is prevented by offering prayers of healing			
48	SCD can be prevented by the use of herbs			
49	The prevalence of sickle cell disease can be reduced by screening newborn babies			
50	SCD can be prevented by eating good food			

IMO ATI IWOYE AWON ODO TI KO SI N'ILE-IWE LORI ARUN FONIKU-FOLAN'DE NI IJOBA IBILE ARIWA ILA-OORUN IBADAN NI IPINLE OYO

ALAYE MOGBO-MOGBA

Si Oludahun,

Oruko mi ni **GANSARI Beatrice Bona**, mo je omo akeko giga ni eka eto Igbelaruge Ilera, ni Ile Eko Isegun nla, Unifasity ti Ilu Ibadan.

Erongba ise yii ni lati se iwadi Imo ati Iwoye awon Odo ti ko si n'ile-iwe lori Arun Foniku-Folan'de ni Ijoba Ibile Ariwa Ila-Oorun Ibadan, Ipinle Oyo.

Ko si idahun to kuna tabi tona lori awon ibeere tia beere/tabi awon gbolohun inu iwe yi; ohun ti a fe ni sise olooto nipa awon idahun re. Jowo kiyesi pe fifi owo si iwe ibeere kii se dandan o. Gbogbo awon idahun ti e ba fun wa ni a o lo lati tun te imo siwaju ati seto idasi ti yoo se iranwo fun sise adinku itankale arun Foniku-Folan'de.

A dupe fun ifowosowopo yin.

- E wa lominira lati ma kopa ninu eto yii. E lee ma pari awon ibeere naa ni akoko to wu yin bi e ba yan lati se bee. A mo riri iranlowo yin bi e ba kopa ninu awon iwadi yii.
- Mogbo-Mogba nisinsin yii ti a ti salaye eko yii fun mi, ti mo si ti loye ohun to wa ninu re, mo gba lati kopa ninu eto naa.

Ibuwolu	Deeti

ABALA KINNI

IBEERE NIPA OLUDAHUN:

- 1. Kinni ojo ori re? (odun) -----
- 2. Ako-n-babo? 1. Ako[] 2. Abo[]
- 3. Esin wo lonse? 1. Kristieni[] 2. Musulumi[] 3. Esin Ibile 4.
- 4. Kinni eya re? 1. Yoruba[] 2.Hausa[] 3. Igbo[] 4. Fulani[] 5.Omiran (so ni pato)-----
- 5. Ipo igbeyawo: 1. Mo ti segbeyawo[] 2. Nko gbeyawo ri[] 3. Ati firawa sile[] 4. Ati ko rawa[] 5. Opo[] 6. Apon[]
- 6. Ipele eko: 1. Nko lo Ile-iwe[] 2. Ile-iwe alakobere[] 3.Girama de aaye kan[] 4. Girama[] 5. Omiran(so ni pato)-----
- 7. Ise to nse: 1. Aranso[] 2. Jorinmorin[] 3.Awako[] 4. Aserunloge[] 5. Oja tita[] 6. Okoowo[] 7. Akose Noosi[] 8. Kosi[]

ABALA KEJI

IMO AWON ODO LORI ARUN FONIKU-FOLAN'DE:

- 8. Nje o tile ti gbo nipa arun Foniku-folan'de? 1. Beeni[] 2. Beeko[]
- 9. Nibo lo ti gbo nipa re? 1. Awon ore[] 2. Ebi[] 3. Ibatan[] 4. Awon onimo ilera[] 5. Ile-iwe[] 6. Lori agbagbe iroyin[]
- 10. Nje o ti gbo nipa arun aami? 1. Beeni[] 2. Beeko[] 3. Ko daju[]
- 11. Nje iyato wa laarin arun Foniku-folan'de ati apeere arun foniku-folan'de? 1. Beeni[] 2. Beeko[] 3. Ko daju[]
- 12. Nje o tile ti se ayewo iru eje too ni (bi beeni dahun ibere 13 ati 14, bi beeko lo si 15 ati 16). 1. Beeni [] 2. Beeko []
- 13. Iru eje wo lo ni? 1.AA[] 2.AS[] 3.AC[] 4.CC[] 5.SC[].
- 14. Kinni idi ti o fi se ayewo eje? 1. Kinle wo ile-iwe[] 2. Ifurasi nipa ilera[] 3. Latari imo ilera[] 4. Ilasile fun igbeyawo[] 5. Awon miran(so ni pato)------
- 15. Kinni idi ti oko tii see? 1. Nko mo nipa re[] 2. Nko mo ibi ti ma ti se[] 3.Mi o ri owo ti maa fi see[] 4. Nko raaye[] 5.Nko ni lo re[] 6. Awon miran(so ni pato)------
- 16. Nje o fe ayewo eje naa bi anfani ba wa lati se bee? 1. Beeni[] 2. Beeko[] 3. Mi o nilo re[]
- 17. Nje o le da eni ti oni arun Foniku-folan'de mo? 1. Beeni[] 2. Beeko[] 3. Ko daju[]

- 18. Bawo lo se fidi e mule pe enikan ni Foniku-folan'de? 1. Sise ayewo eje[] 2. Ara gbigbona[] 3. Imu ton rin[] 4. Irisi eni naa[] 5. Ko daju[]
- 19. Nje enikeni ninu ebi re ni arun Foniku-folan'de? (bi beeni dahun 20, bi beeko, fo 20). 1. Beeni[] 2. Beeko[] 3. Ko daju[]
- 20. Bawo ni eni naa si je si o? 1. Iya[] 2. Baba[] 3. Arabinrin[] 4. Arakunrin[] 5. Aburo/Egbon obi lokunrin[] 6. Aburo/Egbon obi lobinrin[] 7. Iya-iya baba[] 8. Baba-Iya Baba[] 9. Omiran[]
- 21. A le ko arun Foniku-folan'de nipa: 1. Ifarakanra[] 2. Oju ojo ti ko dara[] 3. Efon[] 4. Wiwa labe oorun[] 5. Lati inu eje awon obi[]
- 22. Awon ami ati apeere nini arun Foniku-folan'de: 1. Irora ninu egungun[] 2. Pipon oju ooro ati ese[] 3. Ki ara fuye/kuru ju bi ojo ori[] 4. Ko si okankan nibe[] 5. Gbogbo eyi to ba wa loke[] 6. Ko daju[]
- 23. Awon to ni Foniku-folan'de ma n: 1. Saba kuru ju egbe won lo[] 2. Tete re won[] 3. Pe dagba to egbe won[] 4. Gbogbo ohun to wa loke[] 5. Ko si Kankan nbe[] 6. Ko daju[]
- 24. Se obinrin to ba ni arun Foniku-folan'de le loyun? 1. Beeni[] 2. Beeko[] 3. Ko daju[]
- 25. Awon emi esu le fa arun Foniku-folan'de si eyan lara: 1. Beeni[] 2. Beeko[] 3. Ko daju[].
- 26. Bawo la se sayewo arun yi? 1. Nipa ayewo eje[] 2. Nipa sise ayewo kokoro aisan iba[] 3. Nipa yiya aworan inu[] 4. Ko daju[].
- 27. Kinni iye omo tara re jipepe ti awon obi to ni arun Foniku-folan'de le bi? 1. Ko si Kankan ninu awon omo[] 2. Gbogbo awon omo[] 3. Idaji ninu awon omo[] 4. Okan ninu merin[] 5. Nko mo[].
- 28.Oogun fun awon to ni arun Foniku-folan'de: 1. Oogun ibile[] 2. Ogun Oyinbo[] 3. Adura[] 4. Nko mo[].

ABALA KETA

IWOYENIPA ARUN FONIKU-FOLAN'DE

S/N	Gbolohun	Mo gba	Mi o mo	Nko gba
29	Enikeni lo le ni eje arun yii			
30	Mi o le ni arun yi lailai			

31	A o le ni arun yii ninu ebi mi lailai			
32	Arun Foniku-folan'de je ise-owo awon ota			
33	Ko si repete nipa arun Foniku-folan'de awon eniyan kan pariwo re kiri ni?			X
34	Eje eniyan le yi pada bo se n dagba si		70	
35	Awon ounje kan ti awon eniyan nje ninu oyun lo nfa arun Foniku-folan'de	2	BI	
36	Ki alaboyun ma rin ninu oorun lo ma nfa arun Foniku-folan'de	DRI		
37	Arun Foniku-folan'de see wo			
38	Arun Foniku-folan'de ma nse akoba fun iseso eniyan			
39	Eni to ni arun Foniku-folan'de le sise bi eni ti nkankan ko se			
40	Akude oju-ojo le sokunfa irora fun awon to ni arun yii			
41	Bi mo ba mo boya mo ni arun yii tabi beeko, yoo renmi lowo lati yan eni ti mo fe fe			
42	Mo le fe eni to ni arun Foniku-folan'de			
43	Gege bi eni to ni arun Foniku-folan'de, mo le fe eni to ni arun Foniku-folan'de			

ABALA KERIN

DIDENA ARUN FONIKU-FOLAN'DE

S/N	GBOLOHUN	BEENI	BEEKO	KO DAJU
			•	
44	A le dena arun Foniku-folan'de nipa gbigba			Y
	adura iwosan		BK	
45	A le dena arun yii nipa idamoran ati sise ayewo			
	saaju igbeyawo	7		
46	A le dena arun Foniku-folan'de nipa fife			
	aya/oko ti eje re tiwa mu	Ö,		
47	A le fi agbo ibile dena Foniku-folan'de			
48	A le se adinku fun itankale arun Foniku-folan'de			
	nipa sise ayewo fun awon omo titun			
49	A le dena arun Foniku-folan'de nipa jije ounje			
	to dara			

JANUERSHY OF BADANILIBRAR'S



MINISTRY OF HEALTH

DEPARTMENT OF PLANNING, RESEARCH & STATISTICS DIVISION

PRIVATE MAIL BAG NO. 5027, OYO STATE OF NIGERIA

17 September, 2018

The Principal Investigator,
Department of Health Promotion and Education,
Faculty of Public Health,
University of Ibadan,
Ibadan.

Attention: Gansari Beatrice

ETHICS APPROVAL FOR THE IMPLEMENTATION OF YOUR RESEARCH PROPOSAL IN OYO STATE

This is to acknowledge that your Research Proposal titled: "Knowledge and Perception of Out-Of-School Youths on Sickle Cell Disease in Ibadan North East Local Government Area, Oyo State" has been reviewed by the Oyo State Ethics Review Committee.

- 2. The committee has noted your compliance. In the light of this, I am pleased to convey to you the full approval by the committee for the implementation of the Research Proposal in Oyo State, Nigeria.
- 3. Please note that the National Code for Health Research Ethics requires you to comply with all institutional guidelines, rules and regulations, in line with this, the Committee will monitor closely and follow up the implementation of the research study. However, the Ministry of Health would like to have a copy of the results and conclusions of findings as this will help in policy making in the health sector.

Wishing you all the best.

Dr. Abbas Gbolahan

Director, Planning, Research & Statistics

Secretary, Oyo State, Research Ethics Review Committee