

**ACCEPTABILITY OF PRENATAL DIAGNOSIS OF SICKLE CELL DISEASE  
AMONGST ADULTS IN UVWIE LOCAL GOVERNMENT AREA, DELTA  
STATE, NIGERIA**

**BY**

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## ABSTRACT

**Background:** Sickle cell disease (SCD) is a serious disease with debilitating effects that cause a lot of pains, discomfort and also leads to short life expectancy. The burden of SCD still remains a serious public health issue globally and also in Nigeria. It is a disease that can be prevented through genetic counselling, prenatal diagnosis (PND) and selective abortion. However little is known about attitudes towards PND and acceptability of PND in Nigeria. Therefore this study aims to determine the acceptability of prenatal diagnosis of sickle cell disease and termination of affected pregnancy (TAP).

**Methodology:** This study was a descriptive and cross sectional community based survey among consenting adults. A total number of 422 respondents were selected and interviewed through a five stage cluster sampling. Data collection was done using a structured questionnaire which was interviewer administered and it provided information on respondents knowledge about SCD, attitude towards SCD, acceptability of PND of SCD and TAP and reasons for acceptability of PND and TAP. Management and analysis of data was carried out using SPSS. Descriptive statistics was used to describe the general characteristics of the study sample. Knowledge score was computed by adding up the scores for all questions on knowledge of SCD and the mean score was used as the cut off for good versus poor knowledge. Similarly, attitude score was computed by adding up the scores of all questions on attitude on a Likert scale and the mean score was used as cut-off for positive versus negative attitude. Chi-square test was used to determine the association between the independent and dependent variables

**Results:** The mean age of respondents was 29.82 (SD= $\pm$  11.36 years). There were 192 males (45.5%) and 230 females (54.5%). There were 352 urban dwellers (83.6%) and 69 rural dwellers (16.4%). About 227 respondents had tertiary level of education (54.0%) where 162 (38.6%), 23 (5.5%) and 8 (1.9%) of the respondents had secondary, primary and no formal level of education respectively. The mean score of the knowledge of SCD was  $14 \pm 2.22$  and mean score for attitude towards SCD was  $34 \pm 4.83$ . Respondents with good knowledge of SCD were 169 (50.1%) and those with positive attitude were 192 (45.5%). The number of respondents who have ever heard of PND was 114 (27.9%) while acceptability of PND and TAP was 48% and 13.2% respectively. Multivariate analysis showed Christians were four more times likely than Muslims to accept PND (OR- 4.53,



95%CI- 1.27 – 16.17) and urban dwellers were about two times less likely than rural dwellers to accept PND (OR- 0.55, 95%CI- 0.31 – 0.99).

**Conclusion:** Findings from this study have shown that less than half of respondents' accepted PND and TAP. Efforts should be made to enlighten the public if this procedure is to be accepted by the public.

**Keywords:** Sickle cell disease, Prenatal Diagnosis, Pregnancy, Attitude towards SCD, and Knowledge of SCD.

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## DEDICATION

I dedicate this work to God Almighty who is the father of all wisdom and to my parents Rev and Mrs Solomon Adams for always being there for me.

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## CERTIFICATION

I certify that this project was duly carried out directly under my supervision and also meets the regulations governing the award of the degree of M.Sc. (Epidemiology) in the Department of Epidemiology and Medical Statistics, Faculty of Public Health, College of Medicine, University of Ibadan.

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## TABLE OF CONTENT

Abstract.....	ii
Acknowledgement.....	iv
Dedication.....	v
Certification .....	vi
Table of contents.....	vii
List of tables.....	x
List of Abbreviations.....	xi

### Chapter One

1.0 Introduction.....	1
1.1 Background.....	1
1.2 Statement of Problem.....	3
1.3 Justification.....	4
1.4 Objectives of the Study.....	5

### Chapter Two

2.0 Literature Review.....	6
2.1 Overview of Sickle Cell Disease.....	6
2.2 Burden of Sickle Cell Disease.....	8
2.3 Risk Factors for Sickle Cell Disease.....	9
2.4 Knowledge of Sickle Cell Disease.....	10
2.5 Effects of Sickle Cell Disease.....	11
2.5.1 Physical Effects.....	11
2.5.2 Clinical Phenotypes.....	12
2.5.3 Psychosocial Effects.....	12
2.5.4 Neuropsychological Complications.....	13
2.5.5 Discrimination and Stigmatization.....	14
2.5.6 Quality of Life.....	14
2.6 Management and Treatment of Sickle Cell Disease.....	14
2.7 Prenatal Diagnosis of Sickle Cell Disease and Termination of Affected Pregnancy.....	17

2.8 Attitude towards Prenatal Diagnosis of Sickle Cell Disease and Termination of Affected Pregnancy.....	19
---	----

2.9 Acceptability of Prenatal Diagnosis of Sickle Cell Disease and Termination of Affected Pregnancy.....	20
---	----

### Chapter Three

3.0 Methodology.....	22
----------------------	----

3.1 Study Design.....	22
-----------------------	----

3.2 Study Area/Setting.....	22
-----------------------------	----

3.3 Study Population.....	22
---------------------------	----

3.4 Inclusion Criteria.....	22
-----------------------------	----

3.5 Sampling Size Determination.....	23
--------------------------------------	----

3.6 Sampling Method.....	23
--------------------------	----

3.7 Data Collection.....	24
--------------------------	----

3.8 Data Management and Analysis.....	24
---------------------------------------	----

3.9 Variable Definition.....	25
------------------------------	----

3.10 Ethical Consideration.....	25
---------------------------------	----

### Chapter Four

4.0 Results.....	26
------------------	----

4.1 Socio-demographic Characteristic.....	26
---	----

4.2 Knowledge about Sickle Cell Disease.....	28
--	----

4.3 Attitude towards Sickle Cell Disease.....	31
---	----

4.4 Acceptability Prenatal Diagnosis of Sickle Cell Disease and Termination of Affected Pregnancy.....	33
--	----

4.5 Reasons for Acceptability of Prenatal Diagnosis.....	36
--	----

4.6 Reasons for Acceptability of Termination of Affected Pregnancy.....	38
---	----

4.7 Factors Responsible for Acceptability of Prenatal Diagnosis of Sickle Cell Disease.....	40
---	----

4.8 Factors Responsible for Acceptability of Termination of Affected Pregnancy.....	43
---	----

4.8 Multivariate Analysis.....	45
--------------------------------	----



## Chapter Five

5.0 Discussion, Conclusion and Recommendations.....	48
5.1 Discussion.....	48
5.1.1 Acceptability of Prenatal Diagnosis of Sickle Cell Disease.....	48
5.1.2 Acceptability of Termination of Affected Pregnancy.....	49
5.1.3 Influence of Factors on Acceptability of Prenatal Diagnosis and Termination of Affected Pregnancy.....	51
5.1.4 Knowledge of Sickle Cell Disease.....	51
5.1.5 Attitude towards Sickle Cell Disease.....	52
5.2 Limitations.....	53
5.3 Conclusion.....	54
5.4 Recommendation.....	54
References.....	55
Appendix.....	63

## LIST OF TABLES

Table 4.1	Distribution of sociodemographic factors.....	27
Table 4.2	Knowledge of sickle cell disease.....	29
Table 4.3	Attitude towards sickle cell disease.....	32
Table 4.4	knowledge of Methods of prenatal diagnosis.....	34
Table 4.5	Acceptability of prenatal diagnosis of sickle cell disease and termination of affected pregnancy.....	35
Table 4.6	Reasons for Acceptability of Prenatal Diagnosis.....	37
Table 4.7	Reasons for Acceptability of Termination of Affected Pregnancy.....	39
Table 4.8	Bivariate analysis of factors likely responsible for acceptability of prenatal diagnosis of sickle cell disease.....	42
Table 4.9	Bivariate analysis of factors likely responsible for acceptability of termination of affected pregnancy.....	44
Table 4.10	Multivariate analysis of significant factors associated with acceptability of prenatal diagnosis.....	46
Table 4.11	Multivariate analysis of significant factors associated with acceptability of termination of affected pregnancy.....	47

## LIST OF ABBREVIATIONS

- HbF Foetal haemoglobin  
HbS Sickling haemoglobin  
HbAS Carrier haemoglobin  
HbA Normal haemoglobin  
WHO World Health Organization  
SCD Sickle cell disease  
PND Prenatal diagnosis  
TAP Termination of affected pregnancy  
OR Odds ratio  
CI Confidence interval

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## CHAPTER ONE

### INTRODUCTION

#### 1.1 Background

Sickle cell disease (SCD) is still a neglected disease in Africa (Weatherall, 2010) despite the recommendation that was made by WHO in 2006, that all African states should include the fight against SCD in their respective national health policies.

It is a hereditary disease caused by mutation of  $\beta$ -globin gene which is located on the short arm of human chromosome II (Ashley -Koch et al, 2000). There is a replacement of glutamic acid by valine at the 6<sup>th</sup> position of the  $\beta$ -globin chain which leads to the formation of the gene HBS responsible for sickle cell disease (Brousse et al, 2014). The global affected birth rate is about 2 per 1000 and three-quarter of this rate is found in Africa which means about 200,000 children are born annually with a severe SCD (WHO, 2008). The disease affects mainly people of African region because it has been shown that it is prevalent generally in Africa and particularly in Nigeria (WHO, 2006). For all the SCD births in Africa, Nigeria accounts for about 75% of such births and ranks number 1 among sickle cell endemic countries in Africa and worldwide (WHO, 2006). The prevalence of SCD is about 20-30 per 1000 live births in Nigeria annually (WHO, 2006), while about 24% of Nigerians are carriers of the sickle cell trait. As a result of this high prevalence, about 150,000 infants are born annually with SCD and about 100,000 will die annually from SCD (WHO, 2006). It is also important to note that SCD accounts for 16% of under-5-mortality in Nigeria yearly as maintained by WHO (Okundi and Victor, 2013). SCD is a serious disease with lots of debilitating effects that cause a lot of pains, discomfort and also leads to short life expectancy. Such effects include psychosocial effects that can be experienced by SCD patients and their caregivers especially mothers who are mainly responsible for their care and upkeep (Tunde-Ayinmode, 2011). Other effects include difficulties experienced by caregivers in coping with adult children affected by SCD (Ohaeri and Shokunbi, 2002), poor academic performance by children affected with SCD (Ezenwosu et al, 2013) and also the effect on family finances which are usually grossly affected in the cause of management of SCD (Brown et al, 2010). SCD also has stigmatizing effects such that those affected have higher levels of depression as compared to the general population as shown by a study carried out in the USA among

African American adults. According to the study, 26% showed higher level of depression and about 32% showed symptoms of depression than the overall population of 9.5% (Jencrette et al, 2005).

Taking a look at all these effects, it is therefore important that SCD should be prevented from occurring and there is a chance that it could be prevented through premarital counselling and making the right partner choices as regards genotype compatibility since it is a hereditary disease. But sometimes, people are still ignorant of this or they might even be aware (Gabriel and Mathew, 2013) and still choose to go ahead to remain with partners with whom their genotypes are not compatible (Alswaldi et al, 2011), thereby increasing the prevalence of SCD by giving birth to children affected with SCD. It could also be prevented through prenatal diagnosis which could lead to termination of pregnancies affected with SCD if so desired, with the hope of reducing the prevalence of SCD.

Prenatal diagnosis (PND) was introduced in Nigeria to determine if a foetus is carrying the gene HBS or not and which would determine if the affected pregnancy is to be terminated (Akinyanju et al, 1999). Studies have shown that acceptability of prenatal diagnosis and termination of affected pregnancies varies across patients, parents and clinicians. In Nigeria, a study showed that 85% of patients, 92% of carrier mothers and 86% of fathers would go through with PND, while 53% of patients, 63% of mothers and 51% of fathers would opt for termination of SCD affected pregnancies (Durosini et al, 1995). Another study carried out in another part of the country among health professionals and students showed that 72.8% are aware of PND, 53% would terminate and 50% knew about where to get PND (Kagu et al, 2004). In another study among health professionals, 75.3% knew that SCD could be prevented by PND, 13.7% were not aware, 11.3% were not sure, 48.2% were not aware of the services in Nigeria and 42.1% will not allow preventive termination of pregnancy (Animasahun et al, 2013). In a study involving parents in Cameroon, about 89.8% accepted the principle and also 62.5% accepted termination of affected pregnancies (Wonkam et al, 2011). A Cameroonian study involving clinicians showed a lower percentage of acceptability of PND (about 36.1%) and also for termination of affected pregnancies (Wonkam et al, 2006).



This study examined the opinions of adults towards PND and termination of pregnancies affected with SCD in the general populace based on the fact that previous studies have been restricted to particular groups and will also try to understand what influence these opinions and how it affects the decisions made by parents.

## 1.2 Statement of Problem

The burden of SCD still remains a serious public health issue globally and also in Nigeria. According to a study based on demographics, the burden of SCD is increasing and will continue to increase. Globally, there was an estimate of about 305,800 of new-borns in 2010 and this would increase to 404,200 in 2050, while in Nigeria, in 2010 the number of new-borns would have been 91,000 and this would increase to 140,800 in 2050 (Piel et al, 2013). Also the study also showed that implementation of basic health interventions like PND for SCD in 2015 would lead to a significant reduction in excess mortality among under-5 children with SCD and if continued by 2050, it could save the lives of 9,806,000 new-borns with SCD globally.

From studies carried out, it is still obvious that not everyone is aware of the effects SCD has on the populace. Awareness and acceptability of PND is still a serious issue as it is influenced by different factors as shown in various studies. A study showed that about 47% would still not terminate pregnancies affected by SCD (Kagu et al, 2004) and another study showed that 47% of patients, 37% of mothers and 49% of fathers would not opt for termination of affected pregnancies due to fear of complications and religious conviction and most of the respondents would still prefer effective genetic counselling as the best means of controlling SCD (Durosinmi et al, 1995). Another study also carried out amongst female health workers showed that 78.6% of doctors, 67.7% of other health workers and 68% of nurses did not accept termination of affected pregnancies (Adeyemi and Adekanle, 2007). In terms of awareness, a study showed that about 75.3% knew about PND and about 48.2% are aware of the service in Nigeria (Animasahun et al, 2012).

All these studies have shown that despite the level of awareness of SCD and PND, SCD is still on the increase. Therefore, there still needs to be more awareness and this could be achieved by examining the opinions of people to help know what areas need to be more



focused on and also know the kind of policies that would be put in place to help individuals in making choices that they would benefit them and at the same time would not be criticized for making such choices by society. However, prenatal diagnosis is still not freely available and it is also expensive (Akinyanju et al, 1999). Nonetheless, if by examining the opinions of individuals and they seem comfortable with it; it might become an area of interest for policy makers.

### **1.3 Justification**

Termination of pregnancies generally in this part of the world is like a taboo and different factors influence opinions of individuals as regards this. However the financial burden of managing SCD is enormous such that a family's income could be grossly affected (Brown et al, 2010). The findings from this study would help influence policies that would enable individuals to become more aware of the dangers that surround giving birth to SCD babies and that they have a choice of either keeping the affected pregnancy or terminating the affected pregnancy and also help policy makers see that PND and termination of pregnancy affected by SCD is acceptable by the populace. Therefore, PND would be made more available and affordable to them. Genetic counsellors would also benefit from this study as the findings could guide them in deciding the best approaches during counselling sessions for either intending couples or intending parents.

Studies have shown that burden of under-5 mortality as a result of SCD, would keep increasing unless preventive method like PND is adopted (Piel et al, 2013). In adopting such method, it is important that the opinion of individuals is examined to determine how such methods would be put place and also if it is acceptable to them regardless of factors that influence their opinions.

### **1.3 Objectives**

#### **1.3.1 General Objective**

This study is to examine the acceptability of PND of sickle cell disease and termination of affected pregnancy among adults.

### 1.3.2 Specific Objectives

- To assess the knowledge of sickle cell disease
- To determine the acceptability of PND of sickle cell disease and termination of affected pregnancy.
- To examine the influence of factors on acceptability of PND
- To examine the influence of factors on acceptability of termination of affected pregnancy.

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## CHAPTER TWO

### LITERATURE REVIEW

#### 2.1 Overview of Sickle Cell Disease (SCD)

Sickle cell disease is a broad term that covers a variety of other diseases that are referred to as abnormalities of haemoglobin and they all have a common characteristic which is the sickling phenomenon whereby there is a change in the shape of the red blood cell from the normal discoid shape to a rigid sickle shape (Milicia & Sally, 1987). This phenomenon results when there is a substitution of a single nucleotide from thymine to adenine in the  $\beta$ -chain of haemoglobin resulting in amino acid valine instead of glutamic acid (Rees et al, 2010) and this is also known as mutation. Africa and Asia have been known to be the birthplace of sickle cell mutation (Adewoyin, 2014). As a result of this substitution, instead of the normal adult haemoglobin (HbA), a structured variant is created (HbS) (Murayama, 1967). This structured variant produced induces the polymerization of Hbs molecules within the red blood cells and this result in sickling of the red blood cells. Sickling occurs when there is absence of oxygen and in the presence of oxygen, unsickling occurs. A repeated occurrence of this could lead to the damage of the red blood cell membrane and therefore rendering the red cells permanently damaged (Adewoyin, 2014).

Sickle cell disease is a genetic disorder disease which can also be referred to as a human hereditary disease and are the most common of human hereditary disease (WHO, 1994). These abnormalities of haemoglobin earlier stated are usually inherited by the offspring of those who carry these genes and these abnormalities are inherited in an autosomal recessive fashion either in the homozygous state or double heterozygous state (Adewoyin, 2014). These inherited abnormalities are expressed in various forms such as sickle cell anaemia, haemoglobin sickle cell disease, sickle beta plus thalassaemia, sickle beta zero thalassaemia and others (Adewoyin, 2014). There are also four main African haplotypes according to the region where they were discovered and one Asian haplotype. They include Senegal, Benin (Nigeria falls here), Bantu (Central African Republic) and Cameroon haplotypes and also the Asian haplotype that could also be referred to as Arab-



Indian (Serjeant, 2013; Lapoumeroulie et al, 1992; Kulozik et al, 1986; Pagnier et al, 1984). The Bantu haplotype is associated with the most severe disease phenotype while the Asian haplotype is associated with a mild phenotype (Steinberg, 2005).

Sickle cell disease has also been associated with malaria such that highest prevalence of SCD is found in regions where malaria parasite is still endemic and this is so because it has been found out that the carrier state (HbAS) is kind of protective against severe malaria. Consequently, the sickle cell trait is kind of preserved since most carriers become survivors of malaria up to adulthood and thereby causing the trait to be manifested in later offspring. Studies have shown that this protection occurs because *Plasmodium falciparum* does not grow well in HbS and therefore this creates a kind of selective pressure that has maintained the sickle cell gene in such endemic areas. This kind of phenomenon is known as balanced polymorphism (Desa and Dhanani, 2003; Allison, 1954). There is still another kind of haemoglobin that is produced in children with SCD that could offer a kind of protection at first thereby hindering the symptoms of SCD from manifesting. This haemoglobin is known as foetal haemoglobin (HbF) and as the child grows, it declines which would then cause symptoms to start manifesting (Watson, 1948). In Sub-Saharan Africa, those with the Bantu haplotype have the lowest HbF expression; hence there is severity of the disease. However, while those with the Senegal and Asian haplotypes have the highest HbF expression, therefore a decrease in severity of disease (Saraf et al, 2013).

Sickle cell disease is also associated with high mortality rate such that most SCD children die in early childhood if they are not properly managed (Makani et al, 2013). Access to appropriate health care plays a major role in the life expectancy of SCD patients. Children born to underprivileged families are mostly affected due to the fact that they might not have access to quality healthcare and as a result very few survive to childhood (Flaming et al, 1979). However, the survival of those who have access to healthcare is still improving at all ages but quality of life and an average life expectancy is still an issue in Nigeria. Nigerian's goal is to attain the life expectancy of Americans which is at 53 years (Akinyanju, 2010).

Symptoms of SCD would include dactylitis also known as hand-foot syndrome which is a painful swelling of the hands or feet as a result of vaso-occlusion, anaemia and invasive



infection with encapsulated bacteria. Children mostly present with dactylitis and it is in infancy or early childhood that most cases present. However, patients with milder form of the disease such as HbSc disease may not present early with symptoms but maybe diagnosed as adults with acute pain or an incidental blood testing (Brousse et al, 2014). SCD can be diagnosed in the laboratory and it is based on the presence of HbS or the absence or reduction of HbA. Available screening test in Nigeria include sodium metabisulphate sickling test and sickle solubility test with a confirmatory test that makes use of electrophoresis and chromatography to confirm for sickle phenotype (Makani et al, 2013).

## 2.2 Burden of Sickle Cell Disease

Sickle cell disease has become one of the most common hereditary diseases globally such that its highest rate of occurrence can be found in the Middle East, Mediterranean regions, South-east Asia and sub-Saharan Africa especially in Nigeria (Modell, 1989 and Serjeant, 1997). With this increase in the rate of occurrence of SCD, it has been recognized as a public health problem by the United Nations during the 63<sup>rd</sup> session of the general assembly that was held in December 2008. However, the World Health Organization had already identified SCD as a major public health problem for the past 25 years (WHO, 1994). It is as a result of this recognition of SCD as a public health problem that lead to the initiation of world sickle cell day which is to be held on the 19<sup>th</sup> of June every year (United Nations press office, 2009). Despite the initiation of this day of awareness globally, SCD is still on the increase. According to a study based on demographics, the burden of SCD is increasing and will continue to increase. Globally, there was an estimate of about 305,800 of new-born in 2010 with SCD and this would increase to 404,200 in 2050, while in Nigeria, as at 2010, the number of new-born with SCD was 91,00 and this would increase to 140,800 in 2050 (Piel et al, 2013).

Although, SCD is said to have originated from the malaria-endemic world, it has spread to other parts of Europe and North America as a result of migration, thereby causing a rise in the burden of SCD globally (Piel et al, 2014). Globally, SCD affects approximately 100 million people of which 5% are carriers (Modell and Darlison, WHO, 2006). With a large population of the world being affected, it also means that there is also an increase in the



number of affected children being born annually. A report by WHO, 1994, shows that affected birth rate is about 2 per 1000. In Africa, SCD is also said to be prevalent (WHO, 2006), especially since it is the most common genetic disorder that affects blacks (Konotey, 1992). Its prevalence is highest in West Africa and this is as a result of the region being a malaria-endemic region (Bernadette and Mathew, WHO, 2008). As a result of this high prevalence, over 200,000 infants are born annually who are affected with SCD and 60% of these infants would die as infants (Bernadette and Mathew, 2008). The burden is also on the increase in Nigeria since it is also a West Africa region. Nigeria accounts for 75% of all SCD births in Africa and this makes Nigeria to rank number 1 among sickle cell endemic countries both in Africa and globally (WHO, 2006). Since Nigeria accounts for a large portion of SCD, there is also a high prevalence rate such that approximately 150,000 infants are born annually in Nigeria who are affected with SCD and about 100,000 infants will die annually from SCD alone (WHO, 2006).

### **2.3 Risk Factors for Sickle Cell Disease**

Sickle cell disease is a disease that has no cure yet but it could be managed properly if it is detected early enough and if there is proper and adequate provision of health care services to patients. The management of SCD would require that certain factors are taken into consideration to facilitate an effective handling of the disease. Such factors are factors that increase the severity of the disease and if not properly handled, they could lead to complications that would become too difficult to handle and reduces the chances of survival of SCD patients.

It is important that SCD patients are always properly hydrated because dehydration could further aggravate the occurrence of episodes of crisis. This is so because SCD patients already have renal concentration defect which leads to frequent and severe dehydration in the presence of vomiting and when this occurs there is a consequent reduction in plasma volume which leads to episode of crisis (Serjant, 1985). Another risk factor that modifies severity in SCD patient is elevated blood pressure, which could lead to the patient having stroke, renal dysfunction, pulmonary hypertension and early mortality (Pegelow et al, 1997, Goedeuk et al, 2008, Ohene –Frcinpong et al, 1998). This elevated blood pressure could be as a result of increase in body mass index due to dietary habits, activity level and



other genetic modifiers (Pegelow et al, 1997, Lamarre et al, 2013, Desai et al, 2012, Oguanobi et al, 2010). Severe infection like pneumococcal infection is also a risk factor especially in children which is a leading cause of morbidity and mortality (Gaston et al, 1986, Ammann et al, 1997, Halasa et al, 2007).

Exposure to extremes of temperature which could be fever or cold exposure also increases the episodes of crisis in SCD patients and also hypoxia which is a state of oxygen deficiency with a very strong drive to correct the deficiency, contributes immensely to the severity of in SCD (Edwin et al, 2011). Malaria has also be considered a risk factor that could intensify severity in SCD patients especially Nigerians (Makani et al, 2013).

#### **2.4 Knowledge of Sickle Cell Disease**

People's perception about SCD varies across individuals such that some individuals are still ignorant of the disease or some of them might even have different kinds of misconception as regards SCD. It is important that people have the right information about SCD such as knowing their genotype, the basis of inheritance, SCD as an inherited disease, complications and how the disease can be diagnosed which is by blood test. There are also certain factors that could influence knowledge of SCD such as age, mother's educational background, being taught about SCD and first-hand experience of the disease (Owolabi et al, 2011).

The knowledge of SCD varies across different groups of people: among students, medical professionals and medical students, parents, mothers and lay people. In a pilot test carried out in United State of America, about 68% misunderstood the basis of inheritance of SCD, which means most people were ignorant of how the disease was being inherited. However, parents who have SCD children had a better knowledge of SCD than those parents who did not have SCD children (Acharya et al, 2009). Amongst lay people in Benin, there was insufficient awareness of SCD such that most of them didn't know that it is a hereditary disease or that the disease could be detected through a genetic test and also did not know about the series of disorders that are induced by SCD (Zounon et al, 2012).

In Nigeria, series of studies have been carried out amongst students, mothers and medical professionals. Among students, there was sufficient knowledge of SCD such that about



81.8% claimed to have heard about SCD, but there was a poor knowledge of the cause of the disease (38.0%) and just about 48.7% knew their genotype. In this same study, it was found out that age, being taught about SCD, mother's educational background, seeing someone suffering from the disease or having lost a relative to the disease influenced the knowledge of SCD (Owolabi et al, 2011). In a more recent study still amongst students, 83.2% were aware of SCD and also they knew that it was an inherited disorder while 54% knew that the disease could be diagnosed through a blood test. However, 25.5% had wrong belief that SCD is caused by evil spirit (Olakunle et al, 2013). The highest level of knowledge was found amongst medical professionals and medical students such that almost all the respondents had heard about SCD (98.7%). Such high percentage is expected since they are in the medical field and should be custodian of information about SCD. However, there was poor knowledge of complications of SCD such that about 24.3% knew of all the complications (Animasahun et al, 2009). Knowledge of SCD amongst mothers was found to be poor with just about 34% who knew about SCD and that it can be inherited (Famuyiwa and Aina, 2009).

## **2.5 Effects of Sickle Cell Disease**

Sickle cell disease is a serious disease that brings about debilitating effects, causes a lot of pain and discomfort in individuals affected with it, and they could also be affected in such a way that they might not be given the same opportunities as those without the disease. Effects include physical effects, clinical phenotypes, psychosocial effects, neuropsychological complications, discrimination and stigmatization. The quality of life lived by such individuals could also be affected such that they are unable to function fully in various aspects of life.

### **2.5.1 Physical Effects**

Depending on the severity of SCD, the body structure of affected patients could be affected such that they could become lanky or could still maintain their normal built. Also, height and body size could be affected especially in childhood where affected children might be shorter and smaller than their mates (Adewoyin, 2014). Teenagers are also not



left out, such that puberty might be delayed and thereby affecting growth. However they usually catch up with their mates as they become adults (Bantler et al, 2006).

### 2.5.2 Clinical Phenotypes

The most common clinical phenotype is vaso-occlusive crisis also known as pain episode which occurs regularly and frequently. Other effects are anaemic crisis, severe bacterial infection especially sepsis, acute chest syndrome and stroke (Adegoke et al, 2014). Anaemic crisis could become severe such that capacity for mobility is reduced and damages to organs such as the liver, kidneys, lungs and the spleen could take place and when there is multiple organ failure, the SCD patient becomes more prone to severe infections, thereby facilitating the death of such patient (Platt et al, 1994). There is another condition that has been noticed amongst male SCD patients as far back in 1934 by Diggs and Ching and this condition is known as priapism. It was first described in 1845 by Tripe as a condition of painful, purposeless, and persistent penile erection. In a study carried out amongst men both in Nigeria and UK, it was also discovered that about 35% suffered from this condition (Adeyaju, 2002).

### 2.5.3 Psychosocial Effects

SCD patients also experience psychosocial effects aside the fact that they have to go through a lot of pain and discomfort. Psychosocial effects have to do with how the disease affects the patients psychologically and also sometimes their social lives. There are various ways in which patients respond to the fact that they have SCD and they sometimes respond because of the way the society sees them and it might not be too healthy for them. Psychosocial effects cut all age groups, that is both children and adults are affected and even sometimes their caregivers are affected as well.

According to various studies that have been carried out, some of these effects are anxiety and depression. It was found out that both adults and children as well suffer from anxiety and depression which is due to the pains they undergo and society's attitude towards them (Steptoe and Anie, 2003). Patients also show varying levels of low self-esteem and feelings of hopelessness which arise due to the fact that they are unable to do what others can do, frequent hospital visits, being absent from school or not being able to go to school



at all (children) and losing job opportunities (adults) (Anie, 2005). Apart from these feelings of anxiety, depression and others shown by SCD children, they also have other feelings like feelings of discrimination, feelings of not likely to be able to achieve much in life, feelings of being a burden to the family, feelings of giving a bad image to the family and fear of dying any time (Tunde-Ayinmode, 2011). Sometimes caregivers are also suffering psychologically, especially mothers who have to bear the burden of taking care of SCD children. Mothers are affected such that they experience a lot of difficulties in caring for them (Ohaeri and Shokunbi, 2002) and there are also financial constraints since so much is spent in caring for them, thereby affecting family finances (Brown et al, 2010). Mothers also feel that they are being deprived of enjoying life the way they want to, since they spend a lot of time in caring for their affected children and might not have time in doing other things for themselves (Tunde-Ayinmode, 2011).

#### **2.5.4 Neuropsychological Complications**

Neuropsychological complications have to do with complications involving the brain and this is usually due to cerebrovascular diseases often experienced by SCD patients and both adults and children alike experience these complications. Cerebrovascular diseases such as ischaemic brain injury or stroke have been found out to be responsible for these neuropsychological complications (Powars, 2000). Such complications include language, verbal problems (Cohen et al, 1994), problems of attention, reduced concentration, executive function (Bebaun et al, 1998; Brown et al, 2000) and learning deficits in reading and mathematics (Armstrong et al, 1996) especially in children. Children who have SCD could also be at risk of not performing well academically due to the fact that they could suffer from possible cognitive and intellectual impairment (Schatz et al, 2002). Also a study carried out in Enugu, showed that there is a poor academic performance amongst children with SCD as compared with children not affected with SCD (Ezenwosu et al, 2013). While in adults, cerebrovascular diseases could lead to complications that could lead to SCD patients suffering from cognitive impairment which includes dementia.



### **2.5.5 Discrimination and Stigmatization**

Sometimes, SCD patients could be discriminated against because they may be viewed as people not capable of doing things non-SCD patients are capable of doing or seen as people to be pitied. As far back as 1973 (National Academy of Sciences), SCD patients were denied certain military jobs because they were seen as people who would incur high insurance premium due to increase in morbidity and mortality (Whitten and Fischhoff, 1974; Janerich et al, 1973).

In some communities, SCD signs and symptoms could be seen and interpreted as attributes that discredit those who are affected and such stigmatization has affected relationships in some homes (Marsh et al, 2011) such that parents accuse one another of being the cause for such stigma. In this same study, women are mostly seen as the cause of SCD in affected children since anything bad comes from the mother.

### **2.5.6 Quality of Life**

The kind of life lived by SCD patients may be altered as a result of the disease. Quality of life can be viewed in terms of social functioning, physical functioning, mental health, general health, emotional health, vitality, physical role functioning, changes in health and pain. Patients' lifestyle is usually affected such that they have to go to the hospitals a lot of time, thereby not having enough time for other activities and this brings about social functioning limitations. Physical activities are usually limited also, since they undergo a lot of pains and as a result of pain, they could develop pain coping mechanisms such as anger, fear and negative thoughts (Kofi et al, 2002).

## **2.6 Management and Treatment of Sickle Cell Disease**

In Nigeria, efforts are being made to improve SCD management practices such that a national policy which would help in putting these practices in place is still under review (Galadanci et al, 2013). Nevertheless, there was a network established in 2010 which comprised of Nigerian physicians, non-governmental organizations and interested bodies both within and outside the country (Galadanci et al, 2013). In view of this, some procedures were outlined which would help in the care and management of SCD patients.



Such procedures include that primary health care workers should be trained appropriately such that they could give good genetic counselling, awareness and education through the help of the media and other key players in every local government area, introduction into the primary school curriculum, early diagnosis of new-born to enable early detection and initiate early commencement of treatment, SCD patients should be seen on regular basis and have access to a minimum level of care and there should be prompt referral to a primary or tertiary institution if there is need for such, new-born screening and establishment of comprehensive SCD centres in all geopolitical zones, and provision of SCD desk in the ministry of health (Galadanci et al, 2013).

Sickle cell disease patients can also be managed through the provision of a well organised holistic care. A study has shown that implementation of holistic care helped in reducing illness, deaths and also contributed greatly to improving the quality of lives of people affected by sickle cell disease especially in developing countries like Nigeria (Akinyanju et al, 2005). A well organised holistic care would include encouraging SCD patients to comply with their treatment regimen, teaching them how to prepare local nutritious food and drinks for themselves and also how they can recognise early signs of sickness. SCD patients are also managed by ensuring that they do not get sick with malaria and this can be achieved by malaria prophylaxis. They can also be given supplements and emergent drugs that they could keep at home for easy access in times of crisis (Akinyanju et al, 2005).

In caring for SCD patients, one must ensure that adequate warmth is provided for them since they are very sensitive to extreme weather conditions (Delicou and Maragos, 2013). It is essential that both patients and their caregivers always have simple analgesics at home in event of a painful episode and also a diary of such episodes is to be kept to help identify the causes of such pains (Ademola, 2014; Makani et al, 2013) which could be as a result of anything ranging from physical activities to stress. Therefore, it becomes necessary that SCD patients are not subjected to undue stress and unnecessary physical exertion and vaccination of both SCD patients is crucial because they can easily be affected with different kinds of infections (Adewoyin, 2014). Sometimes, there is a case of nocturnal enuresis which occurs in children and some adults and this can be managed by



either waking the child up at night to urinate or ensuring that no drinking of any fluid at night, or the drug demopressin is administered which studies have shown that it has 60% response rate (Figuroa et al, 1995). How to manage pregnant women with SCD is also very important and this involves preconceptual counselling about prenatal diagnosis and the risks that accompany dealing with both pregnancy and SCD. They should also be stopped from taking hydroxyurea three months before pregnancy occurs or immediately there is confirmation of pregnancy (Ballas et al, 2009).

There is another aspect of managing SCD which can be referred to as psychological interventions which involves psychoeducation and cognitive behavioural therapy. The first one has to do with improving the knowledge and understanding of patients as regards SCD and it is believed that it will help them to cope better psychologically. This improvement of knowledge could be done through peer or family groups, where people get to discuss their issues and concerns, thereby making everyone in the group benefit from the experiences and coping mechanisms of others (Anie et al, 2000). Cognitive behavioural therapy deals with the changing of inappropriate self-defeating thoughts in order for SCD patients to lead a more productive and satisfying life and also help to improve their mood in psychological coping ability (Anie et al, 2002). It has also been proven that cognitive behavioural therapy reduces pain in adults with SCD (Thomas et al, 1999).

However, SCD patients can be treated in several ways such that early morbidity and mortality can be prevented (Gaston et al, 1986). Vaso-occlusion, a common pain episode among SCD patients could be treated using simple analgesia like paracetamol, antibiotics are given to SCD patients to prevent secondary infection since they are already immunocompromised, hydration is usually encouraged because they already have a renal concentration defect known as hyponatremia that causes them to vomit a lot (Scrjeant, 1985) and also when there is a sudden drop in haemoglobin level, blood transfusion can be carried out (Milicia and Sally, 1987). In case of a chronic renal failure, SCD patients could be treated with a combination of hydroxyurea and an angiotensin which help in reducing protein loss (Sasongko et al, 2013). They also suffer from chronic leg ulcers which can be treated by applying compression bandages, regular dressing of the ulcers, skin grafting



and ensuring that they are given zinc complements (Minniti et al, 2010). Another condition known as proliferative retinopathy can be treated using laser treatment which may be beneficial to those with progressive retinopathy (Brousse et al, 2014). Neonatal screening could also be seen as another way to help reduce mortality such that early detection of the disease would mean giving early treatment and attention to patients.

Sickle cell disease could also be managed through some measures of control and prevention since it is a hereditary disease. This will include premarital counselling of couples before getting married to enable them make right partner choice as regards genotype compatibility and sensitization campaigns both on SCD and premarital sex (Oludare et al, 2013) to prevent further transmission of the disease. Premarital counselling is done after a genetic screening has been carried out which involves detecting carriers of the disease and those couples at risk. Couples at risk are therefore advised and at the same time its non-directive, thereby making it a decision they have to make on their own (Abdel-Meguid et al, 2000). Therefore, more efforts should be increased on premarital counselling since the prevalence of SCD is high in Nigeria (Oludare et al, 2013). Another option to reduce the prevalence of SCD would be by pre-natal diagnosis and selective abortion which is still controversial and not readily available in Nigeria (Adewoyin, 2014).

## **2.7 Pre-natal Diagnosis Of Sickle Cell Disease and Termination of Affected Pregnancy**

According to Sickle Cell Organization in Nigeria, pre-natal diagnosis (PND) is a test that can be carried out on an unborn child to determine if the unborn child is affected with a particular disease of interest. In the case of SCD, this test is done to determine if the unborn is carrying the sickle cell gene (HbSS), especially when a couple is at risk of giving birth to a sickle cell child. PND can be carried out in three different ways which include chorionic villus sampling, foetal blood sampling and amniocentesis. A test is usually chosen depending on the stage of the pregnancy and the position of the placenta.

Chorionic villus sampling is carried out for a pregnancy that is about eight weeks old and should not exceed 14 weeks. A sample of chorionic villi is taken from the placenta either



via a trans cervical or transabdominal route. DNA from this sample is then analysed to see if the foetus genes for haemoglobin is normal or abnormal. It takes about one week for the results of this test to be ready. In the case of foetal blood sampling, the test is carried out for pregnancies that are between 18 and 22 weeks. It is done by collecting the blood sample of the baby through the baby's umbilical cord. This blood sample is then analysed for any abnormality in haemoglobin structure. The last method which is the amniocentesis is seen as the easiest test to perform for PND of SCD and the results usually takes a minimum of three weeks to be ready. However, in all of these methods of PND, the risk that is usually attributed to them is the risk of miscarriage. Although, it has not been properly proven that any of these tests could lead to miscarriage, it could still be seen as a risk in carrying out any of these tests and other factors could be responsible for miscarriage (Akinyanju et al, 1999). After any of these tests might have been carried out, the subsequent results determine the decision that would be made by a couple. If the result of these tests show any abnormality in haemoglobin structure, a couple could decide to terminate the affected pregnancy or decide to carry a pregnancy to term and be prepared to accept all the responsibilities that comes with giving birth to a child with SCD.

PND and termination of pregnancy affected by SCD has ethical issues ranging from the safety of the procedures to other kind of issues. The safety issue is about the extent to which the termination of affected pregnancy carried out would be termed safe without any form of complications, especially in a developing country like Nigeria. Apart from the concerns about the safety of the procedures, the decision to terminate an affected pregnancy could be viewed as both being right or wrong and also whether it is also right or wrong to give birth to such a child and allow the child to go through all the pains and discomfort associated with SCD. Religious beliefs and personal morals are also ethical issues to deal with because they influence the decisions made by those faced with making the choice of either terminating an affected pregnancy or not or those giving out the counsel on PND and termination of affected pregnancy. Even though PND could be accepted by many, it is still not widely available and payment for services is high thereby making it an ethical issue (Joseph, 2009).



PND was initiated in Nigeria in 1999 as a result of a lot of information that was generated from genetic counselling and other sources (Akinyanju et al, 1999) and because it is an invention of modern technology, it was seen as a procedure that could be effectively carried out. Introduction of PND to Nigeria was through an initiative of the Sickle Cell Club Lagos, Nigeria and the collaboration of the British Council, the department of Obstetrics and Gynaecology of University Teaching Hospital and the Nigerian Institute of Medical Research. During the initiation of PND, a significant level of success rate was achieved. There were about 113 pregnant women who were recruited for the PND procedure and 124 samples were analysed throughout the period of the research. The results of the analysis showed that 23 were found to carry the HbSS gene, 29 carried the HbAA gene and 67 had the HbAS gene. At the end of the PND test, 96% of women with foetus carrying the sickle-celled gene opted for termination of such pregnancies (Akinyanju et al, 1999).

Although PND services are not relatively available in Nigeria (Adewoyin, 2014), individuals still know about the procedure and why it is done. A study among health professionals and medical students in Lagos Teaching Hospital, showed that about 75.3% knew that SCD could be prevented by PND and 48.2% were not aware of the service in Nigeria (Animasahun et al, 2012). In another study carried out in the North-Eastern part of Nigeria still among health professionals and students, 72.8% had heard about PND and only 14.2% knew where the services were available in Nigeria and 85.8% did not know that PND services were available (Kagu et al, 2004).

## **2.8 Attitude towards Prenatal Diagnosis of Sickle Cell Disease and Termination of Affected Pregnancy**

There are varying attitudes towards PND and especially termination of pregnancy affected by SCD, because it is a very sensitive issue. Individuals have different reasons for either accepting or rejecting termination of affected pregnancy. In a country like Nigeria, from studies that have been carried out, people are not quite comfortable with the term abortion which also means termination of pregnancy even if it was legally permitted.



Religion plays a major role in individual's attitude towards PND and termination of affected pregnancy since Nigeria is a very religious country. A study showed that more Christians said no to termination of affected pregnancy even though they support PND (Kagu et al, 2004). Apart from religion, others justify their rejection based on moral reasons (Durosinmi et al, 1997). However, there are some who accepted both PND and termination of affected pregnancy and their reason was simply because they didn't want to deal with the problems associated with managing SCD children (Durosinmi et al, 2004).

## **2.9 Acceptability of Prenatal Diagnosis of Sickle Cell Disease and Termination of Affected Pregnancy**

Termination of pregnancy affected by SCD is a very sensitive issue since it involves the life of an unborn child. It is one thing to go through with PND and it is another to accept the termination of an affected pregnancy and as such the acceptability of PND and termination of pregnancy affected by SCD is dependent on the opinions of individuals and such opinions are influenced by several factors. Such factors include religion, personal beliefs and morals. Therefore, not everyone who accepts PND would also accept termination of affected pregnancy.

Results from a study carried out among a sample of parents of sickle cell anaemia patients in Cameroun, showed that a higher proportion accepted the principle (89.8%) and there was a lower proportion (62.5%) who would actually go through with termination of affected pregnancy (Wonkam et al, 2011). Also, in a study carried out among patients of SCD, the same trend evolved with a higher proportion accepting PND (89.2%) and just 40.9% would consider terminating an affected pregnancy (Wonkam et al, 2013). There were a lower proportion of those who would go through because they felt abortion was wrong and this was due mainly to their religious beliefs and also morals.

In the first study carried out when PND was first introduced in Nigeria, which was among pregnant women with risk of having SCD children, about 96% of women who had affected fetuses opted for termination of such pregnancies (Akinyanju et al, 1999). The case is different for a sample of Nigerian population whereby only 45% would accept termination of affected pregnancy and a higher proportion (73%) would decide not to

terminate an affected pregnancy (Durosinmi et al. 1997). Among female health workers, one would have thought the proportion of acceptability would be higher but it is even much lower such that 21.4% of the doctors, 32.0% of the nurses and 32.3% of health workers would accept termination of pregnancy affected by SCD (Adeyemi and Adekunle, 2007).

Therefore, it could be deduced from all of these studies that it is easier for individuals to accept PND but more difficult to go through with termination of affected pregnancy.



## CHAPTER THREE

### METHODOLOGY

#### 3.1 Study Design

This study was a cross sectional community based survey to determine the acceptability of prenatal diagnosis and termination of pregnancy affected by sickle cell disease amongst consenting adults.

#### 3.2 Study Area/Setting

This study was carried out in Delta State, a South-Southern state, Nigeria. Delta state is made up of 25 Local Government Areas (LGA) and has its capital at Asaba. Uvwie Local Government Area was the LGA of interest of study and it is located in Delta Central senatorial district. The LGA has a land size of 95,896km<sup>2</sup> with a population of 188,728 according to the National Population Census of 2006 and also has ten (10) enumeration wards.

Uvwie LGA has a mixed population of both urban and rural dwellers. It comprises of people from different ethnic groups but the original ethnic group is of the uvwie tribe. The urban dwellers are made up of literates, semi-literates and illiterates, where some are professionals, businessmen and petty traders. It could be said that the economy of this community is of the average income class since most people are gainfully employed or involved in one business or the other. While in the rural area, there are more of illiterates and semi-illiterates who are more involved in petty trading.

#### 3.3 Study Population

This study was carried out among consenting men and women of at least 18 years of age and residents of Uvwie Local Government Area in Warri, Delta State.

#### 3.4 Inclusion Criteria

All consent giving individuals above the age of 18

### 3.5 Sample Size Determination

The sample size formula for cross sectional studies was used in determining the sample size for this study. It is stated as follows:

$$n = Z^2 \cdot P \cdot q / d^2 \text{ (Kasiulevicius et al, 2006)}$$

Where  $Z=1.96$

$n$  = Sample size

$d$  = Precision = 0.05

$p$  = proportion of a sample of Nigerians that would opt for termination of affected pregnancies (Durosini et al, 1997) which is 0.45.

$q = 1 - p$  which is  $1 - 0.45$

This gave a sample size of about 380 which is equivalent to  $n$ . To adjust for non-response, 10% was chosen as non-response rate and dividing 380 by this rate (0.9), minimum sample size was about 422.

### 3.6 Sampling Method

A minimum of 422 consenting adult respondents was selected by carrying out a cluster sampling and this was done in five (5) stages

STAGE 1: Uvwie Local Government has ten (10) wards from which two (2) wards were randomly selected. A minimum number of respondents of about 211 were allocated to each ward.

STAGE 2: From the two wards, two communities were randomly selected which gave a total of four communities.

STAGE 3: From these communities, about five streets were randomly selected from each of them with about twenty one individuals per street.



STAGE 4: The number of houses selected was based on the number allotted to each street to attain the twenty one individuals per street.

STAGE 5: Consenting adults in selected houses were then interviewed from the selected streets until the required sample size was attained.

### 3.7 Data Collection

Data collection was carried out through the use of interviewer-administered structured questionnaire. The questionnaire used was in five sections. Section A was designed to determine the socio-demographic status of the respondents. Section B provided information on respondents' knowledge about SCD. Section C provided information on attitudes of respondents towards SCD while Section D provided information on knowledge and attitude of respondents towards PND and termination of pregnancy affected by SCD. Section E provided information on reasons respondents have concerning their attitudes towards PND or SCD. Section F provided information on respondents views on preventive policies and introduction of PND in Nigeria. A pre-test of the questionnaire was carried out after which some of the questions were modified

### 3.8 Data Management and Analysis

Data was managed and analysed using SPSS (statistical package for social sciences). Descriptive statistics such as frequencies and proportions was used to describe the general characteristics of the study sample. Chi-square test was used to determine the association between the independent and dependent variables and only variables found to be statistically significant were further analysed using multiple logistic regression to check for confounders. Factors that were significant at  $p < 0.2$  were included in the logistic regression. Odds ratios from the logistic regression analysis were presented with a 95% confidence interval (CI). A probability level of  $p < 0.05$  was accepted as being statistically significant. Knowledge score was computed by adding up the scores for all questions on knowledge of SCD and the mean score was used as the cut off for good versus poor knowledge. Similarly, attitude score was computed by adding up the scores of all questions on attitude on a Likert scale and the mean score was used as cut-off for positive versus negative attitude.

### 3.9 Variable Definition

**Independent Variables:** They include age, gender, marital status, location, level of education, religion, ethnicity, knowledge of SCD and attitude towards SCD

**Dependent Variables:** They include acceptability of prenatal diagnosis of SCD and termination of affected pregnancy

### 3.10 Ethical Consideration

Ethical approval was obtained from the Oyo State Ethical Review Board. The study posed no harm and only willing participants were interviewed without coercion, undue influence or intimidation. Participants were informed about the nature of the study and given consent forms to read and sign. All their concerns and questions were answered before data collection commenced in which they had the right to withdraw with no penalty. Confidentiality and anonymity of participants was assured as no incriminating information or identifier was collected.



## CHAPTER FOUR

### RESULTS

#### 4.1 Socio Demographic Characteristics

There were 422 respondents, 192 males (45.5%) and 230 females (54.5%). The respondents were aged between 18 and 79 years with a mean age of 29.82 (SD=± 11.36 years). A large number of the respondents resided in the urban parts of the Local Government Area, 352 (83.4%) and with 69 (16.4%) residing in the rural area. A sizeable number of the respondents were singles 242 (57.3%), 168 (39.8%) were married, 3 (0.7%) were divorced, 2 (0.3%) were separated and 7 (1.7%) were widowed. Respondents who had primary education were about 31 (7.4%), 162 (38.6%) had secondary education and 227 (54.0%) had tertiary education. Three hundred and eighty one (91.8%) of respondents were Christians, 22 (5.3%) were Muslims. Sixty nine (16.7%) of the respondents were Yoruba, 71 (17.2%) were Igbo, 21 (5.1%) were Hausa, 72 (17.4%) were Uvwie and 180 (43.6%) belonged to other types of ethnicity. Table 1 shows the distribution of socio demographic factors.

**Table 4.1 Distribution of socio demographic factors**

<b>Variables</b>	<b>Frequency</b>	<b>%</b>
<b>Age(Years)</b>		
18-19	62	14.7
20-24	89	21.1
25-29	66	15.6
30-34	61	14.5
35&above	144	34.1
<b>Gender</b>		
Male	192	45.5
Female	230	54.5
<b>Location</b>		
Urban	352	83.4
Rural	69	16.4
Missing	1	0.2
<b>Marital Status</b>		
Single	242	57.3
Married	168	39.8
Divorced	3	0.7
Separated	2	0.5
Widowed	7	1.7
<b>Level Of Education</b>		
Primary	31	7.4
Secondary	162	38.4
Tertiary	227	53.8
Missing	2	0.5
<b>Religion</b>		
Christianity	381	90.3
Islam	22	5.2
Missing	19	4.5
<b>Ethnicity</b>		
Yoruba	69	16.4
Igbo	71	16.8
Hausa	21	5.0
Uvwie	72	17.1
Others	180	42.7
Missing	9	2.1



#### 4.2 Knowledge about Sickle Cell Disease (SCD)

Respondents were asked different questions to determine their knowledge about SCD.

Knowledge score was computed by adding up the scores for all questions on knowledge of SCD and the mean score (14) was used as the cut off for good versus poor knowledge.

About 168 (49.9%) had poor knowledge and about 169 (50.1%) had good knowledge of SCD. The frequency is as shown below in table 4.2

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**Table 4.2 Knowledge of SCD**

<b>Variable</b>	<b>Frequency*</b>	<b>%</b>
<b>Heard of sickle cell disease</b>		
Yes	411	97.4
No	10	2.4
I don't know	1	0.2
<b>Family member affected by SCD</b>		
Yes	28	6.8
No	385	93.2
<b>Best Description of SCD</b>		
Inherited Blood Disorder	319	81.4
Infectious Disease	26	6.6
Sexually Transmitted disease	16	4.1
Fatal illness	31	7.9
<b>Acquiring SCD</b>		
Blood transfusion	32	7.8
Inherited from mothers	8	2.0
Inherited from fathers	26	6.3
Inherited from fathers & mothers	319	77.8
Sexual intercourse	18	4.4
Others	7	1.7
<b>SCD is curable</b>		
Yes	73	17.7
No	213	51.6
I don't know	127	30.8
<b>Symptoms of SCD</b>		
Swelling of hands & feet	94	24.0
Headache	75	19.1
Acute anaemia	183	46.7
Episodes of pain	195	49.7
Frequent infections	138	35.2
Delayed growth	125	31.9
Vision problem	37	9.4
Malaria	85	21.7
Vomiting	28	7.1
Stomach ache	27	6.9
<b>Effects of SCD</b>		
Severe debilitating pain	194	51.2
Stroke	119	31.4
Infections	149	39.3
Organ damage	148	39.1

\*Frequencies don't add up to the sample size due to missing values



**Table 4.2 Knowledge of SCD (continued)**

<b>Variable</b>	<b>Frequency*</b>	<b>%</b>
<b>Appropriate time to test for SCD</b>		
During pregnancy	196	48.9
After childbirth	116	28.9
At childhood	59	14.7
At adulthood	30	7.5
<b>Crisis in SCD</b>		
Pain episodes	263	66.2
Confusion episodes	68	17.1
Crying episodes	46	11.6
Others	20	5.0
<b>Heard of genotype</b>		
Yes	385	92.3
No	24	5.8
I don't know	8	1.9
<b>Genotype responsible for SCD</b>		
AA	9	2.4
AS	33	8.7
SS	332	87.8
SC	4	1.1
<b>Heard of genetic counselling</b>		
Yes	190	46.5
No	152	37.2
I don't know	67	16.4

\*Frequencies don't add up to the sample size due to missing values

### 4.3 Attitude towards Sickle Cell Disease

Respondents showed different attitude towards SCD based on the kind of questions that were asked and the attitude was measured using a Likert scale. Attitude score was computed by adding up the scores of all questions on attitude and the mean score (34) was used as cutoff for positive versus negative attitude. Respondents with negative attitude were 223 (53.7%) and those with positive attitude were 192 (45.5%). Table 4.3 shows the attitude of respondents.



**Table 4.3 Attitude towards SCD**

<b>Variable</b>	<b>Strongly Agree (%)</b>	<b>Agree (%)</b>	<b>Undecided (%)</b>	<b>Disagree (%)</b>	<b>Strongly Disagree (%)</b>	<b>Total*</b>
SCD is God's will	48(11.6)	20(4.8)	38(9.2)	154(37.1)	155(37.3)	415(100)
SCD is satan/evil spirit work	26(6.3)	82(19.8)	49(11.8)	134(32.3)	124(29.9)	415(100)
SCD patients live normal life	37(8.9)	85(20.5)	57(13.7)	188(45.3)	48(11.6)	415(100)
SCD patients are nuisance	9(2.2)	39(9.4)	68(16.4)	202(48.7)	97(23.4)	415(100)
It is safe to eat %share food with SCD patients	167(40.2)	164(39.5)	39(9.4)	38(9.2)	7(1.7)	415(100)
A disease to be ashamed of	17(4.1)	53(12.8)	50(12.0)	202(48.7)	93(22.4)	415(100)
SCD should be kept secret	11(2.7)	35(8.4)	37(8.9)	229(55.2)	103(24.8)	415(100)
SCD is contagious	6(1.4)	16(3.9)	58(14.0)	170(41.0)	165(39.8)	415(100)
SCD patients are a burden	11(2.7)	55(13.3)	56(13.5)	189(45.5)	104(25.1)	415(100)

\*Frequencies don't add up to sample size due to missing values

#### 4.4 Acceptability of Prenatal Diagnosis (PND) of Sickle Cell Disease and Termination of Affected Pregnancy (TAP)

Amongst the 422 respondents interviewed, 377 made a decision on whether Prenatal diagnosis was acceptable to them or not. Respondents were asked if they have ever heard of PND and 114 (27.9%) said yes while 295 (72.1%) said no. Those who have ever heard of PND were asked if they knew the methods of PND and their responses are shown below in table 4.4. Respondents who were willing to accept prenatal diagnosis of sickle cell disease were 181(48.0%) while 196(52.0%) were against it as shown below in table 4.5. Also, amongst the respondents interviewed, 386 made a decision as regards termination of pregnancy affected by sickle cell disease of which 51(13.2%) accepted it while 335(86.8%) kicked against it. This is shown below in table 4.5.



**Table 4.4. knowledge of Methods of Prenatal Diagnosis**

Methods	Frequency	
	(Yes)	%
Amniocentesis	27	28.7
Chorionic villus sampling	15	16.0
Foetal blood sampling	21	22.3

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**Table 4.5 Acceptability of PND and TAP**

Variable	Yes (%)	No (%)	Total*
Acceptability Of Prenatal Diagnosis Of Sickle Cell Disease	181(48.0)	196(52.0)	377(100)
Acceptability Of Termination Of Affected Pregnancy	51(13.2)	335(86.8)	386(100)

\*Frequencies don't add up to sample size due to missing values

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#### 4.5 Reasons for Acceptability of Prenatal Diagnosis

Respondents gave several reasons for accepting prenatal diagnosis which ranged from fear of future child health, fear of maternal health, prevention, determination of SCD status, preparation by caregivers/parents, educational purpose, to enable proper decision making and to give awareness. The frequencies are shown below in table 4.6.

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**Table 4.6 Reasons for Acceptability of Prenatal Diagnosis**

Reasons	Frequency	%
Fear of future child health	6	1.4
Fear of maternal health	2	0.5
Prevention	13	3.1
Preparation by parents to face challenges	20	4.7
To determine the status	63	14.9
To educate	2	0.5
To enable proper decision making	10	2.4
To give awareness	9	2.1



#### 4.6 Reasons for Acceptability of Termination of Affected Pregnancy

Respondents gave several reasons for accepting termination of affected pregnancy which include death is still inevitable, financial reasons, eradication of SCD, fear of future child health, protecting the future, reduction of SCD, to prevent trouble for the parents/caregiver, to prevent unnecessary suffering and to avoid any form of confusion.

The frequencies are shown below in table 4.7.

**Table 4.7 Reasons for Acceptability of Termination of Affected Pregnancy**

Reasons	Frequency	%
Death is still inevitable	2	0.5
Financial reasons	5	1.2
Eradication of SCD	1	0.2
Fear of future child health	1	0.2
Protecting the future	6	1.4
Reduction of SCD	3	0.7
The child will become a nuisance	1	0.2
It's the only way out	2	0.5
To avoid confusion	2	0.5
To prevent treatment of reoccurring illness	1	0.2
To prevent trouble for parents	2	0.5
Unnecessary Suffering	14	3.3



#### 4.7 Factors Responsible for Acceptability of Prenatal Diagnosis (PND) of Sickle Cell Disease

Bivariate analysis was done to determine the relationship between acceptability of PND of sickle cell disease and certain factors. Acceptability of PND of sickle cell disease was used as the dependent variable while age, location, marital status, level of education, religion, attitude towards sickle cell disease, knowledge about sickle cell disease and having a family member affected by the disease were used as independent variables. The results are as shown in Table 4.8 below. There was no statistically significant relationship between gender and acceptability of PND, where more of females accepted PND (48.8%) with a p-value of 0.744. A statistically significant relationship was found between location of respondents and acceptability of PND ( $p=0.023$ ) such that though there were more urban respondents who accepted PND (140, 45.2%) there was a higher percentage of acceptability amongst rural respondents (60.6%). Based on educational status, no statistically significant relationship was found to exist ( $p=0.875$ ), but there was a higher level of acceptability amongst respondents with tertiary status (49.3%). There was no statistically significant relationship between marital status and acceptability of PND ( $p=0.891$ ) but a higher level of acceptability was shown amongst respondents who were single (48.3%).

Based on religion, there was a higher level of acceptability amongst the Christians (50.4%) than the Muslims and the relationship was found to be statistically significant ( $p=0.005$ ). Among the various age groups, there was a higher acceptability amongst respondents in the age group of 20-34 (53.7%) with lowest acceptability among respondents in the age group of 35 & above (39.4%) but the relationship was statistically non-significant ( $p=0.051$ ). In terms of attitude towards sickle cell disease, respondents with positive attitude had a higher level of acceptability (49.2%) than those with a negative attitude (47.2%) and the relationship was also statistically non-significant ( $p=0.705$ ). Respondents who had a poor knowledge about sickle cell disease had a higher level of acceptability (50.0%) than those with good knowledge about sickle cell disease with a lower level of acceptability (46.3%) and the relationship was found to be statistically non-significant ( $p=0.513$ ). Respondents who had a family member affected by

sickle cell disease had a higher level of acceptability (55.6%) than those who had no family member affected (47.0%), although the relationship was statistically non-significant ( $p=0.423$ ).

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**Table 4. 8 Bivariate analysis of factors likely responsible for acceptability of PND**

Variable	Acceptability of Prenatal Diagnosis of Sickle Cell Disease		Total*	Chi Square	P- Value
	Yes (%)	No (%)			
<b>Gender</b>					
Male	81(47.1)	91 (52.9)	172(100)	0.11	0.74
Female	100 (48.8)	105 (51.2)	205(100)		
<b>Location</b>					
Urban	140 (45.2)	140(45.2)	310(100)	5.20	0.02
Rural	40 (60.6.)	26( 39.4)	66(100)		
<b>Education</b>					
Primary	13 (52.0)	13 (52.0)	25(100)	0.27	0.88
Secondary	66 (46.5)	76 (53.5)	142(100)		
Tertiary	103 (49.3)	106 (50.7)	209(100.0)		
<b>Marital Status</b>					
Single	101 (48.3)	108 (51.7)	209(100)	0.02	0.89
Ever married	80 (47.6)	88 (52.4)	168(100)		
<b>Religion</b>					
Christianity	174 (50.4)	171 (49.6)	345(100)	7.81	0.01
Islam	3 (16.7)	15 (83.3)	18(100)		
<b>Age</b>					
<20	32 (43.2)	42 (56.8)	74(100)	5.96	0.05
20-34	95 (53.7)	82 (46.3)	177(100)		
35 & above	41 (39.4)	63 (60.6)	104(100)		
<b>Attitude Towards SCD</b>					
Negative attitude	93 (47.2)	104 (52.8)	197(100)	0.14	0.70
Positive attitude	88 (49.2)	91 (50.8)	179(100)		
<b>Knowledge About SCD</b>					
Poor knowledge	79(50.0)	79(50.0)	158(100)	0.43	0.51
Good knowledge	68 (46.3)	79 (53.7)	147(100)		
<b>Family Member Affected With SCD</b>					
Not affected	166 (47.6)	183 (52.4)	349(100)	0.64	0.42
Affected	15 (55.6)	12 (44.4)	27(100)		

\*Frequencies don't add up to sample size due to missing values

#### 4.8 Factors Responsible for Acceptability of Termination of Affected Pregnancy

Bivariate analysis was done to determine the relationship between acceptability of termination of pregnancy affected by sickle cell disease and several factors. Acceptability of termination of affected pregnancy (TAP) was used as the dependent variable while factors such as gender, age, marital status, level of education, religion, attitude towards sickle cell disease, knowledge about sickle cell disease and having an affected family member were used as the independent variables. The results are shown in Table 4.9 below.

The relationship between gender and acceptability of TAP was found to be statistically non-significant ( $p=0.853$ ) where the acceptability of both the male gender was low (13.6%) and also the female gender was low (12.9%). Among the urban and rural dwellers, acceptability was quite low with the urban slightly lower (13.1%) than that of rural dwellers (13.8%) and this relationship was statistically non-significant ( $p=0.876$ ). Acceptability of TAP varied across different level of education such that secondary level of education had the lowest acceptability (7.6%), followed by none/primary level of education (8.3%) and tertiary had the highest acceptability (17.5%) and the relationship was statistically significant ( $p=0.019$ ). Religion had no statistically relationship with TAP ( $p=0.272$ ), although acceptability was relatively low with Christians being in the lead (14.2%) and Muslims having a much lower acceptability (5.3%). Relationship based on age group was found also to be statistically non-significant ( $p=0.134$ ) with respondents in the age group of  $<20$  having the lowest acceptability (6.6%) while respondents in age group 20-34 had the highest acceptability (13.5%). Respondents with negative attitude towards sickle cell disease was found to have lower acceptability (10.4%) while respondents with positive attitude towards sickle cell disease had a higher acceptability (16.4%), though the relationship was found to be statistically non-significant ( $p=0.086$ ). In terms of knowledge about sickle cell disease, respondents with poor knowledge had a higher acceptability (15.5%) while respondents with good knowledge had a lower acceptability (13.3%) but the relationship was statistically non-significant ( $p=0.583$ ). Respondents having a family member not affected by sickle cell disease had a lower acceptability (12.5%) while respondents who had a family member affected had a higher acceptability (18.5%) which was statistically non-significant (0.402%).



**Table 4.9 Bivariate analysis of factors likely responsible for acceptability of termination of affected pregnancy**

Variable	Acceptability of Termination of Pregnancy Affected By SCD		Total*	Chi Square	P-Value
	Yes (%)	No (%)			
<b>Gender</b>					
Male	24 (13.6)	153 (86.4)	177(100)	0.03	0.85
Female	27 (12.9)	24 (13.6)	209(100)		
<b>Location</b>					
Urban	42 (13.1)	278 (86.9)	320(100)	0.02	0.88
Rural	9 (13.8)	56 (86.2)	65(100)		
<b>Education</b>					
None/Primary	2 (8.3)	22 (91.7)	24(100)	7.88	0.02
Secondary	11 (7.6)	133 (92.4)	144(100)		
Tertiary	38 (17.5)	179 (82.5)	217(100)		
<b>Religion</b>					
Christianity	50 (14.2)	303 (85.8)	353(100)	1.21	0.27
Islam	1 (5.3)	18 (94.7)	19(100)		
<b>Age</b>					
<20	5 (6.6)	71 (93.4)	76(100)	4.03	0.13
20-34	29 (15.8)	154 (84.2)	183(100)		
35 &above	14 (13.5)	90 (86.5)	104(100)		
<b>Attitude Towards SCD</b>					
Negative attitude	21 (10.4)	180 (89.6)	201(100)	2.94	0.08
Positive Attitude	30 (16.4)	153 (83.6)	183(100)		
<b>Knowledge About SCD</b>					
Poor Knowledge	25 (15.5)	136 (84.5)	161(100)	0.30	0.58
Good Knowledge	20 (13.3)	130 (86.7)	150(100)		
<b>Family Member Affected By SCD</b>					
Not affected	46 (12.8)	312 (87.2)	358(100)	0.70	0.40
Affected	5 (18.5)	22 (81.5)	27(100)		

\*Frequencies don't add up to sample size due to missing values

#### 4.8 Multivariate Analysis

The variables in the bivariate analysis that were statistically significant at probability level of 0.2 were further analysed using the binary logistic regression model. The result of the multivariate analysis is presented in Table 4.10 and Table 4.11 below.

Results from the analysis show that Muslims are four times less likely to accept PND than Christians. This result was found to be statistically significant (OR- 4.526, CI- 1.267 – 16.169). The relationship between location and PND was also found to be significant (OR- 0.552, CI- 0.307 – 0.992). Other factors had association with PND but were not significant.

Results from the analysis for TAP shows that no association was found to be significant amongst all the factors that were likely to be associated with its acceptability.



**Table 4. 10 Multivariate Analyses of Significant Factors Associated with Acceptability of PND**

<b>Variable</b>	<b>Odds Ratio</b>	<b>Confidence Interval (95%)</b>	<b>P- Value</b>
<b>Religion</b>			
Islam (Ref)			
Christianity	4.62	1.31 – 16.32	0.02
<b>Location</b>			
Rural (Ref)			
Urban	0.55	0.31 – 0.99	0.03
<b>Age</b>			
<20(Ref)			
20-34	1.59	0.91 – 2.79	0.10
35 and above	0.83	0.44 – 1.55	0.55

**Table 4.11 Multivariate Analysis of Significant Factors Associated with Acceptability of TAP**

Variable	Odds Ratio	Confidence Interval (95%)	P- Value
<b>Education</b>			
Primary(Ref)			
Secondary	0.90	0.18 – 4.60	0.83
Tertiary	1.94	0.41 – 9.07	0.40
<b>Attitude</b>			
Negative(Ref)			
Positive	0.80	0.42 – 1.54	0.50
<b>Age</b>			
<20(Ref)			
20-34	0.56	0.19 – 1.70	0.30
35 and above	1.08	0.53 – 2.21	0.83



## CHAPTER FIVE

### DISCUSSION, CONCLUSION AND RECOMMENDATION

#### 5.1 DISCUSSION

In this study, less than half of respondents (48%) accepted prenatal diagnosis (PND) of sickle cell disease (SCD) and a very low proportion (13.2%) accepted termination of affected pregnancy. Socio-demographic factors such as location, religion and education were found to be significantly associated with acceptability of PND and TAP. Also, examining the knowledge of SCD, it was found that about half of the respondents had a good knowledge of SCD.

##### 5.1.1 Acceptability of Prenatal Diagnosis (PND) of Sickle Cell Disease (SCD)

The acceptability of PND from this study was reported by half of respondents. This was quite expected because PND is a procedure still quite unknown to many Nigerians especially since it is not a disease experienced by most of the populace. It was found out from this study that about two third of the respondents had never heard of PND and just heard it for the first time in the process of administering the questionnaire. This could be the reason why there was a low acceptability of PND amongst the study population. However in a study carried out by Durosinmi et al (1995) amongst female SCD patients and parents of SCD patients, the acceptability was quite high even though most of the respondents only became aware of PND at the point of interview. This high acceptability could be as a result of first-hand experience of the disease by the study population and also maybe their desire not to want others suffer from it. Also in another study carried out in Cameroon by Wonkam et al in 2011 and 2013 amongst a sample of parents of SCD patients and SCD patients, acceptability of PND was relatively high in both cases (89.8% and 89.2%).

These results show that there could be higher acceptability of PND if the public is more informed of such procedure because those who didn't accept it had different reasons such as they didn't understand what it entails, some were concerned about the safety of both mother and child, some others think it would encourage abortion and others didn't see any



need for it since the foetus cannot be cured of the disease before birth. However those who accepted PND also had reasons for acceptance. Such reasons include determining the status of the unborn to enable caregivers or parents to know the necessary action to be taken, thereby helping them prepare for the challenges ahead associated with SCD and some respondents felt early detection of SCD could help reduce severity of the disease. Other reasons for acceptability of PND are prevention of SCD and fear of future child and maternal health. Determining the status of the unborn was a more frequent reason amongst respondents for acceptability PND. Therefore enlightenment of the public could improve the level of acceptability and it could become a preventive method for SCD.

### 5.1.2 Acceptability of Termination of Affected Pregnancy (TAP)

Acceptability of TAP in this study is relatively low compared to other previous studies. The acceptability reported by Durosinmi et al (1997) was higher than that of this study where about half of the respondents accepted PND and the study was carried out amongst well-informed educated Nigerians. In another study by Kagu et al (2004), acceptability was reported to be about half and study population was health professionals and students in North Eastern Nigeria. Taking a look at these studies, it could be said that the results are quite different due to the kind of study population used. A higher level of acceptability is expected from such population because they are expected to be quite informed since they are health professionals unlike this study population which was just the general public. Studies carried out in Cameroon amongst SCD patients and parents of SCD patients also showed a higher acceptability as compared to this study. In one study amongst parents of SCD patients, acceptability was relatively high (Wonkam et al, 2011), while in another study amongst SCD patients, acceptability was a little less than average (Wonkam et al, 2013). These results also showed that the kind of population used for the study most likely determined the level of acceptability. It is quite obvious that despite the fact that acceptability of PND could be high, the willingness to accept TAP is low from this study and these findings are quite the same with findings from other studies (Durosinmi et al, 1995; Adeyemi and Adekunle, 2007) where acceptability of TAP was also lower than acceptability of PND regardless of the population involved. In these studies mentioned, the study population was a sample of doctors and nurses (Adeyemi and



Adekunle, 2007) where about quarter and one third of the respondents accepted TAP respectively. This was quite low because one would have expected a higher level of acceptability since they are medical personnel.

Findings from this study show that respondents accepted TAP based on reasons such as the effect treatment and management of SCD has on the income of parents or caregivers, and also they felt it could help reduce SCD. Other reasons include how TAP could help prevent unnecessary suffering for the child after birth since death is still inevitable for the patient, and also helps to avoid confusion for parents. A study carried out amongst female SCD patients and parents of SCD patients had similar reasons for acceptance of PND and the reasons are societal emphasis on perfection and previous experience in the management of SCD patients (Durosinmi et al, 1995). Another study carried out amongst a sample of parents of SCD patients have also shown similar reasons for accepting TAP which include the fear of having another child with SCD, fear of future child health and negative family life experience of SCD (Wonkam et al, 2010). In a study in the United Kingdom, the reason for consideration of TAP was due to the severity of the disease (Ahmed et al, 2006).

Furthermore, low acceptability of TAP could also be attributed to the fact that abortion is looked down upon culturally and religiously in this part of the world. Most of the respondents rejected TAP basically due to religious and moral reasons, while some others were more concerned about complications that would arise from such procedure. Some of the respondents rejected TAP because they are aware of the fact that abortion is illegal in Nigeria. Previous studies have also shown that these reasons are in order for not accepting TAP. In one study amongst health professionals and students North Eastern Nigeria, major reason for rejecting TAP was religious reason (Kagu et al, 2004) while in another study, findings showed that reasons for rejecting TAP were religious and moral reasons (Durosinmi et al, 1997). Similar reasons were also given in a study carried out amongst parents of SCD patients in Cameroon and the reasons were ethical and religious considerations (Wonkam et al, 2010) and in a study amongst SCD patients still in Cameroon, the main reason was ethical reason (Wonkam et al, 2013).



### 5.1.3 Influence of Factors on Acceptability of Prenatal Diagnosis and Termination of Affected Pregnancy

A number of socio-demographic factors and other factors (attitude towards SCD and knowledge of SCD) that could be responsible for respondents' acceptability of PND and TAP were considered and their association was determined. There were several associations but not all of them were significant. On further analysis of the significant associations, only one association was statistically significant.

Location of respondents was found to be a significant factor associated with acceptability of PND. Respondents who lived in the rural area were found to be two more times likely to accept PND of SCD than those in the urban area. This kind of result is strange because one would have expected that those in the urban area should be more receptive towards such a procedure. Religion was also found in this study to be a significant factor such that Christian respondents were more likely to accept PND than respondents who were Muslims.

Education was a significant factor responsible for respondents' decision concerning termination of pregnancy affected by SCD. Respondents with primary level of education or those with no education at all, were more than two times less likely to accept termination of affected pregnancy than those with secondary or tertiary level of education. These results are quite different from other studies such that findings from other studies showed that factors like societal perfection was associated with acceptability of TAP (Durosini et al, 1995) and in Cameroon factors like unemployment and single marital status were associated with acceptability of TAP (Wonkam et al, 2010).

### 5.1.4 Knowledge of Sickle Cell Disease

Examining the level of knowledge of SCD amongst respondents, this study found out that an average of the population has a good knowledge with a mean score of 14. This finding is in line with findings from other studies such as those of Alao et al (2009) where about an average of study participants had good knowledge of SCD and the study population was students of a higher institution. However in a study amongst secondary school students, a high percentage claimed to have heard of SCD but only one third knew the



cause of SCD (Owolabi et al, 2011). From this study, only about an average of the respondents knew severe debilitating pain as one of the effects of SCD and about one third knew organ damage as one of the complications of SCD. This is quite expected since only an average of the population has a good knowledge of SCD. However, these findings are in order with findings from another study amongst health professionals and students, where about one quarter knew most complications and about an average knew some of the complications while about one third had the lowest knowledge about complications (Animasahun et al, 2009). In a study amongst Christian students, knowledge level of SCD was relatively high (Moronkola and Fadairo, 2006). Findings from this study also revealed that a very low percentage of the population preferred childhood as the best time to test for SCD whereas in another study, about one third of study participants preferred childhood as the best time to test for SCD (Animasahun et al, 2009). This study also found out that most respondents have never heard of genetic counselling which is quite unusual, since a high percentage of them have formal education and it was expected of them to know what genetic counselling is. However in another study amongst Christian university students, about two third knew what genetic counselling was (Moronkola and Fadairo, 2006). Respondents were also asked if they could describe SCD and a high percentage of them described it as an inherited blood disorder and could be inherited from both mother and father. In a study amongst new undergraduate tertiary students, there was a severely deficient knowledge of the transmission of SCD (Adewuyi, 2000).

All of these findings make up the level of knowledge of SCD and from these findings, it could be said that SCD is quite known amongst the public but it could still be improved with more enlightenment either from the Government or Non-Governmental bodies, so that they could have access to the right information about SCD.

#### **5.1.5 Attitude towards Sickle Cell Disease**

Attitude of respondents towards sickle cell disease were examined and this study found out that more than half of the population have negative attitude towards SCD while less than half of the population have a positive attitude towards SCD. From the responses, it was quite obvious that most of them had wrong perspective about SCD such that some even felt SCD is contagious and some felt it was not healthy to share food with SCD



patients. Findings from a study amongst secondary school students in Jos showed that a low percentage had wrong belief such that they felt SCD was caused by evil spirit and a higher percentage also showed wrong attitude involving stigmatization (Olakunle et al, 2013). The wrong belief mentioned in this study corresponds with some of the questions asked to determine attitude of respondents towards SCD in this present study. But in another study carried out amongst Christian students, a good number of them had a positive attitude towards SCD. However, a study carried out amongst SCD patients in Lagos found out that they also felt the public had negative attitude towards SCD because they lack proper orientation about SCD (Anie et al, 2010). It was also found out that relative of SCD patients felt SCD caused lower intelligence in SCD patients (Ohaeri and Shokunbi, 2001). A study in United States of America also mentioned societal response to SCD which is most time a form of negative attitude towards SCD (Jenerette et al, 2005).

Findings from this study and other studies have shown that there is a lack of awareness about SCD and most people have a poor orientation about the cause of the disease, how to relate with SCD patients and also have wrong perceptions about SCD patients and the disease itself. The public needs to be more knowledgeable about SCD and this could only happen if there is more awareness and proper orientation.

## 5.2 LIMITATIONS

One limitation of this study is that study participants may not be representative of the entire public since only a sample of Nigerian population was used. Therefore, generalization of results should be done with caution. Recall bias cannot be exempted from this study as some of the respondents found it hard to answer some of the questions that had to do with knowledge about SCD without thinking for a long time. Responses are likely prone to social desirability bias because some respondents would want to give favourable answers.



### 5.3 CONCLUSION

Findings from this study have shown that prenatal diagnosis is still a procedure not known by many especially the public at large since this was a community based study. Efforts towards enlightenment would help increase acceptability of PND by the public.

Location and religion were associated with PND and this association was statistically significant while the level of education was found to be associated with TAP and this association was also statistically significant.

### 5.4 RECOMMENDATION

The following recommendations are hereby made based on the results of this study:

1. Findings from this study have shown that there is a lack of awareness as regards prenatal diagnosis. Therefore, an awareness programme can be initiated where the public can be sensitized concerning PND.
2. Prenatal diagnosis could also be introduced as a policy in Nigeria which would enable the public to have more access to the service.
3. Further research could be carried out with a larger sample size to enable proper generalization of results.
4. Knowledge and attitude of SCD could be improved by giving the public the right information about SCD.
5. This research could be done differently such that people with affected family members are recruited into the study.

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## APPENDIX 1

### INFORMED CONSENT FORM

#### ACCEPTABILITY OF PRENATAL DIAGNOSIS OF SICKLE CELL DISEASE AND TERMINATION OF AFFECTED PREGNANCY

Dear Respondent,

My name is Eseoghene Adams, a Postgraduate student of the Department of Epidemiology and Medical Statistics, Faculty of Public Health, University of Ibadan, Oyo State. This questionnaire is an attempt to gather important information in order to determine the acceptability of prenatal diagnosis and termination of pregnancy affected by sickle cell disease. **DO NOT WRITE YOUR NAME ON THE QUESTIONNAIRE.** Please note that the completion of the questionnaire is entirely voluntary and all information gathered will be treated with utmost confidentiality. Thanks for taking your time to complete this questionnaire. Your truthful responses will contribute important information to help determine the awareness and acceptability of prenatal diagnosis and termination of pregnancy affected by sickle cell disease. As part of my responsibilities, only the researcher, members of the researcher's staff and representatives from the **Oyo State Ethical Review Committees** may have access to these records.

#### Statement of study participant giving informed consent:

Now that the study has been well explained to me and I fully understand the content of the study, I hereby agree to participate in the study.

Date: \_\_\_\_/\_\_\_\_/\_\_\_\_  
number: \_\_\_\_\_

Signature: \_\_\_\_\_

Phone

#### Statement of research assistant obtaining informed consent

I have fully explained this research to the respondent and have given sufficient information including about risk and benefits to make an informed decision.

Name: \_\_\_\_\_

Signature: \_\_\_\_\_

Date: \_\_\_\_\_

\_\_\_\_/\_\_\_\_/\_\_\_\_



# QUESTIONNAIRE

## ACCEPTABILITY OF PRENATAL DIAGNOSIS OF SICKLE CELL DISEASE AND TERMINATION OF AFFECTED PREGNANCY

1. Identification number

### SECTION A

#### SOCIO DEMOGRAPHIC INFORMATION

2. Age \_\_\_\_\_

3. Gender Female  Male

4. Location Urban  Rural

5. Marital status Single  Married  Divorced  Separated  Widowed

6. Level of education No formal Education  Primary  Secondary  Graduate

Postgraduate

7. Religion Christianity  Islam  Traditional  Others

8. Occupation Business  Petty trader  Professional  Farmer  Labourer

Others  Please specify \_\_\_\_\_

9. Ethnicity Yoruba  Igbo  Hausa  Uvwie  Others  Please specify \_\_\_\_\_

## SECTION B

### KNOWLEDGE ABOUT SICKLE CELL DISEASE (SCD)

10. Have you ever heard of sickle cell disease? Yes  No  I don't know

11. If yes, which of the following best describes sickle cell disease?

Inherited blood disorder  Infectious disease  Sexually transmitted disease  Fatal illness

12. Sickle cell disease is acquired through which of the following ways? (Tick one answer)

Blood transfusion  Inherited from: Mother alone  Father alone  Mother and father

Sexual intercourse  Others  Please specify \_\_\_\_\_

13. Do you think sickle cell disease is curable?

Yes  No  I don't know

14. What do you think are the symptoms of Sickle cell disease? (Tick as appropriate)

Swelling of hands and feet  Headache  Acute Anaemia  Episodes of pain  Frequent

infections  Delayed growth  Vision problems  Malaria  Vomiting  Stomach ache

15. Sickle Cell Disease can cause (Tick as appropriate)

Severe debilitating pains  Stroke  Infections  Organ damage

16. What time do you think is the appropriate time to test for sickle cell disease? (Tick one option)

During pregnancy  After childbirth  At childhood  At adulthood

17. What do you understand by crisis in sickle cell disease? (Tick one option)



Pain episodes  Confusion episodes  Crying episodes  Others  Please specify \_\_\_\_\_

18. Have you ever heard of the word genotype? Yes  No  I don't know

19. If yes, which of the following is the genotype responsible for sickle cell disease?

AA  AS  SS  SC

20. Have you heard of genetic counselling for sickle cell disease? Yes  No  I don't know

21. If yes, what do you think it is?

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**SECTION C**

**ATTITUDES TOWARDS SICKLE CELL DISEASE**

For questions 22-30, tick one option for each question

S/N	ATTITUDES	Strongly Agree	Agree	Undecided	Disagree	Strongly disagree
22	Sickle cell disease is God's will					
23	Sickle cell disease is satan/evil spirits work					
24	Sickle cell disease patients live a normal life					
25	Sickle cell disease patients are nuisance to the society					
26	It is safe to share food or eat with					

	sickle cell disease patient				
27	Sickle cell disease is a disease to be ashamed of				
28	Sickle cell disease should be kept secret				
29	Sickle cell disease is contagious				
30	Sickle cell disease patients are a burden to the society				

31. Do you have any family member affected by sickle cell disease?

Yes  No  I don't know

**SECTION D**

**KNOWLEDGE AND ATTITUDE TOWARDS PRENATAL DLAGNOSIS AND TERMINATION OF PREGNANCIES AFFECTED BY SICKLE CELL DISEASE**

32. Have you heard of a test carried out on an unborn child to determine its sickle cell disease status? (Prenatal diagnosis) Yes  No  I don't know

33. If yes, which of the following are methods of this test (prenatal diagnosis) for sickle cell disease? (Tick as appropriate)

Ultra sound  Amniocentesis  Simple blood test  Chorionic villus sampling  Fetal blood sampling

34. Should prenatal diagnosis be used to test for sickle cell disease? Yes  No  I don't know

35. If yes, what are your reasons?

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36. If no, what are your reasons?

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37. Are you in support of prenatal diagnosis for other diseases?

Yes  No  I don't know

38. Should termination of pregnancy affected by sickle cell disease be carried out?

Yes  No  I don't know

39. If yes, what are your reasons?

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40. If no, what are your reasons?

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**SECTION F**

**ATTITUDES TO PREVENTIVE POLICIES AND INTRODUCTION OF PRENATAL DIAGNOSIS AS A POLICY IN NIGERIA**

For questions 41-44, tick one option for each question

S/N	ATTITUDES	Strongly	Agree	Undecided	Disagree	Strongly
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36. If no, what are your reasons?

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37. Are you in support of prenatal diagnosis for other diseases?

Yes  No  I don't know

38. Should termination of pregnancy affected by sickle cell disease be carried out?

Yes  No  I don't know

39. If yes, what are your reasons?

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40. If no, what are your reasons?

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**SECTION F**

**ATTITUDES TO PREVENTIVE POLICIES AND INTRODUCTION OF PRENATAL DIAGNOSIS AS A POLICY IN NIGERIA**

For questions 41-44, tick one option for each question

S/N	ATTITUDES	Strongly	Agree	Undecided	Disagree	Strongly
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		agree				disagree
41	Genetic counselling would help reduce the occurrence of sickle cell disease					
42	Prenatal screening of pregnant women would help prevent the occurrence of sickle cell disease					
43	Screening for sickle cell disease should be done for only families at risk					
44	Prenatal diagnosis of sickle cell disease should be introduced as a policy in Nigeria					

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UI/UCH EC Registration Number: NHREC/05/01/2008a

**NOTICE OF FULL APPROVAL AFTER FULL COMMITTEE REVIEW**

**Re: Acceptability of Prenatal Diagnosis and Termination of Pregnancy affected by Sickle Cell Disease among Adults in Warri, Delta State**

UI/UCH Ethics Committee assigned number: UI/EC/16/0055

Name of Principal Investigator: **Eseoghene Patience Adams**

Address of Principal Investigator: Department of Epidemiology & Medical Statistics,  
 College of Medicine,  
 University of Ibadan, Ibadan

Date of receipt of valid application: 02/03/2016

Date of meeting when final determination on ethical approval was made: N/A

This is to inform you that the research described in the submitted protocol, the consent forms, and other participant information materials have been reviewed and given *full approval by the UI/UCH Ethics Committee.*

This approval dates from 28/07/2016 to 27/07/2017. If there is delay in starting the research, please inform the UI/UCH Ethics Committee so that the dates of approval can be adjusted accordingly. Note that no participant accrual or activity related to this research may be conducted outside of these dates. *All informed consent forms used in this study must carry the UI/UCH EC assigned number and duration of UI/UCH EC approval of the study.* It is expected that you submit your annual report as well as an annual request for the project renewal to the UI/UCH EC early in order to obtain renewal of your approval to avoid disruption of your research.

*The National Code for Health Research Ethics requires you to comply with all institutional guidelines, rules and regulations and with the tenets of the Code including ensuring that all adverse events are reported promptly to the UI/UCH EC. No changes are permitted in the research without prior approval by the UI/UCH EC except in circumstances outlined in the Code. The UI/UCH EC reserves the right to conduct compliance visit to your research site without previous notification.*



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**Professor Catherine O. Falade**  
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 Chairperson, UI/UCH Ethics Committee  
 E-mail: [uiuchec@gmail.com](mailto:uiuchec@gmail.com)