

**PERCEIVED PSYCHOSOCIAL IMPACT AND COPING STRATEGIES AMONG PEOPLE LIVING WITH SICKLE CELL DISEASE IN A LOCAL GOVERNMENT OF OYO STATE, NIGERIA**

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**ABSTRACT:** *In Nigeria, even globally, various studies on sickle cell disease tend to generalize a predisposing factor of sickle cell disease in our society but nevertheless, there is yet a comprehensive study on the psychosocial impact of Sickle Cell Disease on the people living with Sickle Cell Disease and the effect it has on their quality of life and the coping strategies in order to reduce the frequency of crises. Methodology: Data for this study were obtained from both primary and secondary source. The primary source include structured questionnaire; a total of 105 copies of questionnaires were distributed randomly to people living with Sickle Cell Disease in hospitals, schools, Churches and Mosques, while the secondary data were sourced through information from current Journals from internet. The data obtained through these sources were analyzed using frequency tables and simple percentage analysis to discuss the findings of the study. Results: This study shows that the level of understanding and knowledge of respondents to psychosocial impact of Sickle Cell Disease and the management/treatment strategies was adequate. This is evidenced in the fact that greater percentage of the respondents agreed with all the options given i.e. Engaging in a particular intimate relationship, Having commitment ambition and industry, Maintaining a positive and cheerful outlook on the current situation, Letting others know what is of concern and enlisting support by organizing an activity and using professional adviser, such as Counselor. Besides the global burden of Sickle Cell Disease is on the increase on daily basis and same has really affected the quality of life of the victims. Also this psychosocial problems occurring concurrently both in Sickle Cell Disease patients and their caregivers was seen to be a phenomenon that can have negative impacts both on the victims and the family as a whole, hence this study suggests that parents should be seen in the context of their families holistically. The clinicians should provide the necessary psychological care and support to both the victims and caregivers in order to have better success of their treatment/management strategies. Conclusion: Therefore it is against this background that Policy makers and Non-governmental bodies should come together to organize public lectures and seminars to deliberate on the remedies to be employed in order to ameliorate the incidence of Sickle Cell Disease (SCD) in our society in order to maintain Healthy Nations.*

**KEYWORDS:** Perceived Psychosocial Impact, Coping Strategies, People, Sickle Cell Disease, Local Government

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## INTRODUCTION

### Background of the study

More than Seven Million babies are born each year with a structural or functional abnormality. Many of these birth defects are caused by the inheritance of a defective gene (Piel., Hay., gupta., Wather & Williams, 2013). Sickle Cell Anaemia (SCA) is an inherited birth disorder from parents to the child. It arises when a baby inherits the gene for sickle haemoglobin (HbS), a structural variant of normal adult haemoglobin (HbA) the protein in the disc-shaped red blood cells that carry oxygen round the body from both its parents. Every cell in the human body contains two full sets of genes from each parent (Piel et al, 2013).

In the same vein, Yawn, Buchanan, Ballas, Hassel and James (2014); and Ohijoungbe and Burnett (2013), stated that sickle cell anaemia (SCA) and drepanocytosis, is a hereditary blood disorder, characterized by an abnormality in the oxygen-carrying haemoglobin molecule in red blood cells, and leads to a propensity for the cells to assume an abnormal, rigid, sickle-like shape under certain circumstances. Sickle cell disease occurs when a person inherits two abnormal copies of the haemoglobin gene one from each parent. Several subtypes exist, depending on the exact mutation in each haemoglobin gene. A person with a single abnormal copy does not experience symptoms and is said to have sickle-cell trait. Such people are also referred to as carriers.

Bras (2011) opined that sickle cell disease occurs due to a mutation of the beta globin gene of haemoglobin, causing a substitution of the glutamic amino acid for valine at position six (6) of the beta chain thereby producing an abnormal haemoglobin called haemoglobin S (HbS), instead of normal haemoglobin, haemoglobin A (HbA). With modified physiochemical characteristics, the molecules of haemoglobin S suffer polymerization and precipitation, leading to a change in form, a deformity of red blood cells which become sickle-shaped. In this case, the viscosity of the blood increases due to the formation of tactoids. Brass went further to say that the inheritance of sickle cell anaemia occurs via an autosomal recessive gene with both parents. In general, asymptomatic carriers of a single affected gene (heterozygous) transmitting the defective gene to their child(ren), who therefore is homozygous (HbSS).

During fetal and early postnatal life, the lack of expression of the Hb SS phenotype is explained by the production of fetal haemoglobin (Hb F) which is sufficient to limit, by dilution, the effects of sickling. As the red cells that emerge from the bone marrow carry increasing amounts of Hb S and smaller amount of Hb F, the results of sickling gradually appear. Therefore, newborns begin to manifest the disease from the sixth month of life, when the amount of Hb F begins to approach adult levels (Brass, 2011).

According to Brass (2011), Sickle cell anaemia is the best known hereditary haematological disorder in human being. In his study, he estimated that 30,000 children are born annually with sickle cell anaemia worldwide and thus it is among the most important epidemiological genetic diseases in Brazil and the world. He went further to say that sickle cell anaemia was originally from Africa and brought to the Americas by the forced immigration of slaves, it is more frequent where the proportion of African descendants is greater (the north eastern region and the states of Sao Paulo, Rio de Janeiro and Minas Gerais). In these regions, they observe new cases of sickle cell disease in every 1000 births and sickle cell trait carriers in every 27 births. It is estimated that approximately 2,500 children are born every year with sickle cell disease in Brazil.

The non-white population in Brazil was estimated at 44.66% by the 2000 population census and from 1% to 6% of them have the Hbs gene, thus favouring the continuation of sickle cell anaemia in what is suggested by Brazilian Scientific Literature as a serious public health problem.

The prevalence of sickle cell disorder in Nigerian is alarming when compared to other African countries in the world. It is estimated that out of 150,000 birth annually, more than 100,000 Nigerian children are born each year with sickle cell disorder. Children affected with this disorder suffer a higher than average frequency of illness and premature death in the first five years of birth.

Available statistical information shows that over 40 million Nigerians are carriers of the 'S' gene. Indeed, this number far exceeds the total population of every other affected African Country and several of them put together. Despite the large number of people with Sickle Cell Disorder, the Nigerian society in general still has a negative image of sickle cell disease and reported negative perceptions and attitude (WHO, 2006)

The psychosocial impact of sickle cell disorder is devastating and worrisome to parents, families, caregiver and even the children affected by the disorder. Children with sickle cell disease are at risk for maladjustment in almost every area of daily functioning. Specifically, sickle cell disease has been associated with several indicators of psychological maladjustment including emotional and behavioural problems, poor self concept and interpersonal functioning, limited athletics abilities (due in part to illness restrictions) and poor academic performance (Noll., Reither., Purtill., Varinata., Gerthardt and Short 2007).

With respect to the family, caregivers to children with sickle cell disease are burdened with emotional and psychological pain, increased family stress and increased financial demands, which is due in part to the unpredictability of pain crises care in sickle cell disease (Moskowits, 2007). Children with sickle cell disease during crises experience severe pains all over their body especially in their legs and back aches. Caregivers to children with sickle cell disease are tasked with the responsibility for managing their child's care, which includes encouraging their child to engage in preventive behaviours, managing pain episodes, teaching coping skills and providing adequate nutrition and hydration. Moreover, parents of children with sickle cell disease often reports a lack of support by family, relatives and friends when their children have crises. This affects the emotional feeling of parents with frustration and hopelessness. As at today, there is yet a medical treatment or healing for the disease. The best management practice of the disease is preventive measure. Most times, this is done of carried out with genetic counseling of prospective or intending married couples in urban cities and advice given by health practitioners on healthy living programme in the media from electronics and print media.

On the family, the psychosocial impacts of sickle cell are worrisome with financial burden inability to get support with nonchalant attitude and inadequate support to parents of children with sickle cell disease. On the children, they experience pain and frustration, lack of care and support during crises, maladjustment and social functioning, visual impairment, loss of friends, incapacitated with love and affection, education, employment and psychosocial devastation.

### **Problem Statement**

In Nigeria, even globally, various studies on sickle cell disease tend to generalize a predisposing factor of sickle cell disease in our society but to the best of the researcher's

knowledge, there has not been a comprehensive study on the psychosocial impact of sickle cell disease in the people with the disease, the study will hopefully fill this gap.

Also, various studies on sickle cell disease have focused on the reason for rise in the trend of sickle cell disease in Nigeria. However, not much have been carried out on the psychosocial impact/effect of sickle cell disease on the parents and other caregivers of the sickle cell disease children/victims, a vacuum which this study intends to fill.

In addition, studies have been carried out on financial burden of the illness (SCD) on caregivers and families, but not much has been examined on the family, social welfare and self help programmes support in relieving the psychosocial burden of disease and consequently, improving the quality of care for the SCD patients, the gap which the research intends to bridge.

This therefore prompted the researcher to carry out study on the psychosocial impact of sickle cell disease and coping strategies adopted.

### **Purpose/Objectives**

#### **Main Objectives**

The main objectives are to explore the Psychosocial Impact of Sickle Cell Disease (SCD) on people living with Sickle Cell Disease (SCD) and their coping styles.

#### **Specific Objectives**

Specific objectives of the study are to:-

1. Assess the knowledge of respondents on causes of sickle cell
2. Examine the incidence of sickle cell among respondent
3. Assess the psychosocial impact of Sickle Cell Disease (SCD) among selected respondents.
4. Investigate the psychosocial impact of sickle cell disease on the parents
5. Investigate the coping strategies adopted.

#### **Research Questions**

1. What does the term sickle cell disease imply among the respondents?
2. What are the incidences of sickle cell disease in the local government?
3. What are the psychosocial impacts amongst people living with sickle cell disease?
4. What are the psychosocial effects of sickle cell disease on careers?
5. What are the specific coping strategies being adopted by people living with sickle cell disease?

## Hypotheses

- There is no significant difference between psychosocial impact and coping strategies among respondents.
- There is no significant relationship between knowledge of causes and demographic characteristics of respondents.
- There is no significant relationship between the knowledge of causes and coping strategies among respondents.

## Significance of the Study

A study of the perceived psychosocial impacts and coping strategies among people living with sickle cell disease in Ogbomoso North Local Government will contribute to the literature on the perceived psychosocial impacts and coping strategies among people living with sickle cell disease in Ogbomoso North Local Government. The study would be useful to the affected people or victims, their parents or caregivers, health care providers and the society at large in broadening their knowledge and understanding on the psychosocial impacts of sickle cell disease and with the coping strategies being employed as well as introduction of social welfare programmes and self-help group programmes, these would help enhance the quality of life of the affected people thereby ameliorate the burdens of care facing the caregivers.

Also, the findings and result of the study will lead to practical application of the treatment strategies and preventive measures of sickle cell disease in order to reduce the prevalence of sickle cell disease to zero level.

This study will also help the prospective marital couples to have full understanding of the importance of genetic counseling for routine haemoglobin genotype determination so that they will not fall victim of this same problem.

It is hoped that with adequate knowledge and awareness of health care providers, parents or guidance on this condition coupled with public education and counseling now being undertaken by the sickle cell club of Nigeria, medical personnel etc. it will be possible to reduce the high incidence of this disease condition in our society.

## Concept of Sickle Cell Disease

Sickle Cell Disease (SCD) also known as Sickle Cell Anaemia (SCA) and Drepanocytosis is a hereditary blood disorder, characterized by an abnormality in the oxygen-carrying haemoglobin molecule in red blood cells. This leads to a propensity for the cells to assume an abnormal rigid, sickle-like shape under certain circumstances. Sickle cell disease occurs when a person inherits two abnormal copies of the haemoglobin gene, one from each parent. Several subtypes exist, depending on the exact mutation in each haemoglobin gene. Sickle cell is associated with a number of acute and chronic health problems, such as severe infraction, attacks of severe pain (Sickle Cell crisis) and stroke, and there is an increased risk of death. (Global Burden of Disease Study, 2013; Yawn et al, 2014).

According to National Heart, Lung and Blood Institute (NHLBI, 2013), Sickle Cell Anaemia is a blood disorder that causes abnormally shaped red blood cells. Normal blood cells are disk-shaped with an indentation in the centre, and they move smoothly through the blood vessels.

But with sickle anaemia, the body produces red blood cells that are shaped like a sickle, or crescent. These cells don't move through the blood stream as easily and they tend to stick and clump together and cause other health complication. Sickle cell anaemia is just one of many forms of sickle cell disease. It is a condition that is passed along from parents to their children. This disease is more common in people of certain ethnicities, including blacks and Hispanics. In the same vein, Clinical Research on Sickle Cell Disease (CRSCD, 2014) stated that sickle cell disease is the most common inherited blood disorder which is caused by a mutation in the haemoglobin-beta gene found on chromosome II. Haemoglobin transports oxygen from the lungs to other parts of the body. Red blood cells with normal haemoglobin (hemoglobin A) are smooth and round and glide through blood vessels. In people with sickle cell disease, abnormal haemoglobin molecules – haemoglobin S – stick to one another and form long, rod-like structures. These structures caused red blood cell to become stiff, assuming a sickle-shape. Their shape causes these red blood cells to pile up, causing blockages and damaging vital organs and tissue.

Also, Welkom (2012) and Yanni et al., (2009), viewed Sickle Cell Disease as one of the most common childhood onset, single – gene disorders, affecting primarily people of African descent. The sickle cell gene causes an abnormality in the iron-rich protein haemoglobin that is responsible for carrying oxygen through the blood and giving blood its red colour. The abnormal haemoglobin causes cells to become “Sickle Shaped” resulting in irregular blood flow (National Heart Lung Blood Institute (NHLBI), 2010). The red blood cell can stick and block the flow of blood to the limbs and organs resulting in pain, organ damage and a low blood count. For one to inherit the disease, two copies of the sickle cell gene (i.e. one from each parent) must be transmitted to the offspring. Thus, children whose parents each carry the trait will have a 25% chance of inheriting the disease. In other words, Sickle Cell Disease (SCD) include a variety of pathological conditions resulting from the inheritance of the sickle haemoglobin (HbS) gene either homozygously or as a compound heterozygote with other interacting abnormal haemoglobin gene. The disease is clinically one of the most important haemoglobinopathies (Monika, 2008).

The most important protein of Red Blood Cells (RBCs) is haemoglobin which consists of four globin chains, each folded around a haem molecule. Haemoglobin delivers oxygen from the lungs to the tissues and carbon dioxide from the tissues to the lungs. The predominant haemoglobin in adulthood is Hb A which consists of two Alpha and two Beta globin chains. Other haemoglobins are HbA<sub>2</sub> and HbF. During intra-uterine development, several globin chains are synthesized with the predominant haemoglobin type during foetal life being Hb F in the first twelve (12) weeks after birth, the Hb F quickly declines, leaving HbA and Hb A<sub>2</sub> as the remaining haemoglobins. The Beta globin gene is found in chromosome II.

A single point mutation in the 6<sup>th</sup> codon leads to substitution of glutamic acid for valine, resulting in an abnormal globin  $\beta$  s. this result in the formation of sickle haemoglobin or (HbS). In Haemoglobin c (Hbc) the same codon is changed by the insertion of lysine. In Hb D, there is a replacement of glutamine for glutamic acid at position B 121, and in HbO the same codon is changed by the insertion of lysine. These haemoglobin, codon inherited with HbS, result in clinically significant SCD. Sickle cell disease also results from the inheritance of HbS with genes from  $\beta$  thalassaemias. The latter result from a wide variety of DNA mutation – that have in common a reduced synthesis of globin chains. The more severe syndrome called Sickle Cell –  $\beta$  O thalassaemia with no HbA, less severe  $\beta$  thalassaemia mutations result in reduced but variable levels of B-chain synthesis and hence levels of HbA. The most common genotype is

homozygous SS disease. S Hemoglobin C (Sc) disease, SB+thalassaemia and SBO thalassaemia are also relatively common.

Furthermore, John (2009), also claimed that sickle cell disease is a serious disease in which the body makes sickle shaped red blood cells “Sickle-Shaped” means that the cells look like crescents instead of the normal disc shape. Under a microscope, normal red blood cells look like dough nuts without holes in the centre. They move easily through blood vessels. Red blood cells contain the iron-rich protein haemoglobin. This gives blood its red colour and carries oxygen from the lungs to the rest of the body. Sickle cells contain abnormal haemoglobin that causes the cells to become sticky and crescent shaped. When the haemoglobin release its oxygen. The stiff, sickle-shaped cells can stick to the lining of the blood vessels. This can damage the lining, creating a “danger” signal that attracts defensive cells. This response may enhance the “stickiness” and lead to more slowing of normal blood flow through the vessel. This reduces oxygen delivery to the tissue supplied by this part blocked vessel. People with sickle cell disease have a lower than normal number of red blood cells because sickle cells don't live as long as normal cells after they leave the bone marrow.

Sickle cell usually die after about 10 to 20 days, compared to normal red blood cells, which live an average of 120 days. The bone marrow can't make new red blood cells fast enough to replace all the dying ones. So this causes anaemia, low blood count that result in fatigue, shortness of breath and related symptoms. Because the cells are made normally, but die too rapidly, this is termed a “haemolytic” (destruction of red cells) anaemia.

### **Incidence of Sickle Cell Disease**

Sickle Cell Disease afflicts up to 100 million people worldwide, predominantly amongst black people in Africa, Europe and the America, Arabian people and these of Asian ancestry (Adegoke & Kuteyi, 2012).

According to Scott et al., (2011), the most common subtype of sickle cell disease worldwide is homozygous sickle cell disease, characterized by the presence of two copies of the  $\beta$ -globin S ( $\beta$ s) mutation that codes for sickle cell haemoglobin (Hbs). Homozygous SCD is variably referred to as sickle cell anaemia, Hb, SS, disease, sickle cell disease SS. The distribution of the  $\beta$ s allele has recently been mapped globally using detailed geo-reference data and displays a close association with the historical distribution of plasmodium falciparum malarial endemicity. Within African, the frequency of  $\beta$ s, and accordingly SS, is highest in low-attitude equatorial regions. The second subtype of sickle cell disease common in Africa is compound heterozygosity for  $\beta$ s and  $\beta$ c (SC). The  $\beta$ c allele is found almost exclusively among people of West African ancestry being most common among those in Burkina Faso and Northern Ghana. Compound heterozygosity with  $\beta$ <sup>±</sup> thalassaemia (S  $\beta$ <sup>+</sup> Thalassaemia) is a form of sickle cell disease that is believed to be rare in most of Sub-Saharan African. In central East and Southern Africa, sickle cell disease is generally assumed to be synonymous with SS disease, although few studies have specifically looked for S  $\beta$ <sup>0</sup> thalassaemia.

In the same vein, WHO (2006) opined that sickle cell anaemia (also known as sickle cell disease) is a common genetic condition due to the haemoglobin disorder – inheritance of mutant haemoglobin genes from both parents. Such haemoglobinopathies, mainly thalassaemias and sickle cell anaemia, are globally widespread. About 5% of the world's population carries genes responsible for haemoglobinopathies. Each year about 300,000 infants are born with major haemoglobin disorders – including more than 200,000 cases of sickle cell

anaemia in Africa. Globally, there are more carriers i.e. (healthy people who have inherited only one mutant gene from one parent) of thalassaemia than that of sickle-cell anaemia, but the high frequency of the sickle cell gene in certain areas leads to a high rate of affected newborns.

Sickle cell anaemia is particularly common among people whose ancestors come from Sub-Saharan Africa, India, Saudi-Arabia and Mediterranean Countries. Migration raised the frequency of the gene in the American continent. In some areas of Sub-Saharan Africa, up to 2% of all children are born with the condition. In broad terms, the prevalence of the sickle cell trait (healthy carriers who have inherited the mutant gene from only one parent ranges between 10% and 40% across equatorial Africa and decreases to between 1% and 2% on the North African coast and <1% in South Africa. This distribution reflects the fact that sickle cell trait confers a survival advantage against malaria and that selection pressure due to malaria has resulted in high frequencies of the mutant gene especially in areas of high malaria transmission. In West African countries such as Ghana and Nigeria, the frequency of the trait is 15% to 30%, whereas in Uganda it shows marked tribal variations, reaching 45% among the Bamba tribe in the West of the country.

Global Burden of Disease study (GBO) 2013 and Yawn Bachanan, Ballas, Hassell and James (2014) stated that almost 300,000 children are born with a form of sickle cell disease every year, mostly in Sub-Saharan Africa, but also in other parts of the world such as the West Indies and in people of African Origin elsewhere in the world. In 2013 it resulted in 176,000 deaths up from 113,000 deaths in 1990. The highest frequency of sickle cell disease is found in tropical regions, particularly Sub-Saharan Africa, tribal regions of India and the Middle-east. Migration of substantial populations from these high prevalence areas to low prevalence countries in Europe has dramatically increased in recent decades and in some European countries. Sickle cell disease has now overtaken more familiar genetic conditions such as haemophilia and cystic fibrosis.

### **Effects of Sickle Cell Disease on the Health Status of The Victims**

According to Christopher (2005), the sickling of red blood cells occurs when partially or totally deoxygenated haemoglobin molecules distort their normal disk shape, producing stiff, sticky, sickle-shaped cells that obstruct small blood vessels and produce vaso occlusion as well as the disruption of oxygen to body tissues. Because tissue damage can occur at multiple foci, patients with sickle cell disease are at risk for other medical complications including but not limited to delayed growth and sexual maturation. Acute and chronic pulmonary dysfunction, stroke, aseptic necrosis of the hip, shoulders, or both sickle cell retinopathy, dermal ulcers and severe chronic pain. The chronicity of the illness combined with frequent hospitalizations for pain and other medical management can contribute significantly to impaired psychosocial functioning, altered intra and intrapersonal relationships and reduced quality of life. In the same vein, Bras (2011) stated that the effects of the phenomena of vaso-occlusion vary in intensity, but include tissue ischaemia, painful episodes, acute osteo-articular or abdominal crises and chronic organic injuries such as functional asplenia, cerebral-vasocular disease and kidney, heart and lung failure, patients require frequent hospitalization.

In children, infections caused by encapsulated bacteria and intra-splenic vaso-occlusion (splenic sequestration are the main causes of mortality). These begin after the first two to three months of life and affect 20-25% of children in the first five (5) years of age. Children, who have overcome this initial barrier, face the effects of chronic vaso-occlusion. Over the years, these small strokes are the determining factor for the impairment of organs, leading to



pulmonary, liver or brain infarction, kidney failure and retardation of growth and sexual maturation, with progressive impairment of multiple organs. These phenomena significantly reduce the quality of life of individuals, increase need for medical care, and diminish the capacity to work and life expectancy.

In their own contributions on the effects of sickle cell disease on the victims. Monika (2008) stated that the clinical manifestations of the disease are quite variable and include related painful vaso-occlusive, haemolytic, aplastic episodes and sequestration crises. Complications affect various organs and systems mainly skeletal, genito-urinary, gastro-intestinal, spleen, hepato-biliary, cardiopulmonary and central nervous system. These changes in life expectancy have shifted the spectrum of clinical problems to an increased focus on chronic organ dysfunction in developed countries.

There is some age specific order to clinical manifestations where dactylitis, acute splenic sequestration and increased susceptibility to infection are common before age 5 years, painful crises, delayed growth and sexual maturation and leg ulcerations and priapism become issues of concern starting in the adolescent period, and chronic and organ complications such as sickle nephropathy and chronic sickle lung disease with pulmonary hypertension become more manifest after age 30 years.

**Painful Crises:** Monika (2008), further disclosed that the hallmark clinical manifestation of sickle cell disease is the acute vaso-occlusive event, or painful episode. This unique type of pain can start as early as 6 months of age, recur unpredictably over a life time. Present as dactylitis of the hands and feet (hand-foot syndrome) and may result in premature closure of the affected epiphysis, leading to shortened deformed bones. Painful events are the top cause of emergency room visit and hospitalizations and are also a measure of disease severity and prediction of early death in adults, sickle pain can be the prodrome of a serious and potential fatal complication of sickle cell disease in some patients (Ballas 2005).

**Infractions:** There are several abnormalities of the immune system in persons with sickle cell disease. The early loss of splenic functions, either as a result of splenic sequestration and subsequent splenectomy or as a result of auto-splenectomy, is a major component in conferring increased susceptibility to encapsulated organisms such as streptococci pneumoniae and salmonella spp, and leading to e.g. pneumococcal sepsis especially in children under the age of 3 years before the advent of prophylactic penicillin administration, children with sickle cell disease were 30 – 600 times more prone to developing invasive pneumococcal disease, manifesting as septicemia or meningitis (Halasa et al., 2007)

### Effects of Major Organ System

- **The Respiratory System/Acute Chest Syndrome**

Global Burden of Disease Study (2013) and Yawn et al., (2014) opined that acute chest syndrome is defined by at least two of the following signs or symptoms: Chest Pain, Fever, Pulmonary Infiltrate or Focal Abnormality, Respiratory Symptoms or Hypoxemia. It is the second-most common complication and it accounts for about 25% of deaths in patients with sickle cell disease, majority of cases present with vaso-occlusive crises then they develop acute chest syndrome. Never the less, about 80% of patients have vaso-occlusive crises during acute chest syndrome. Also amongst the chronic cardiopulmonary

complications of sickle cell disease, pulmonary hypertension has emerged as the major threat to the well being and longevity of patients with sickle cell disease.

- **Aplastic Crises**

Aplastic crises are acute worsening of the patient's baseline anaemia, producing pale appearance, fast heart rate, and fatigue. This crisis is normally triggered by parvovirus B 19, which directly by invading the red cell precursors and multiplying in and destroying them. Parvovirus B 19 infection almost completely prevents red blood cell production for two to three days. The shortened red cell life of sickle cell disease patients results in an abrupt, life-threatening situation. Global Burden of Disease (GBD, 2013).

- **Haemolytic Crisis**

Haemolytic crises are acute accelerated drops in haemoglobin level. The red blood cells breaks down at a faster rate, this is particularly common in patients with coexistent G6PD deficiency. Global Burden of Disease (GBD, 2013).

- **Other**

Another recognized type of sickle crisis, acute chest syndrome, is characterized by fever, chest pain, difficulty breathing and pulmonary infiltrate in a chest x-ray. This can be triggered by painful crisis, respiratory infection, bone-marrow embolisation or possibly by atelectasis.

### **Psychosocial Impacts of Sickle Cell Disease on the Victims**

According to Adegoke and Kuteyi (2012), Sickle Cell Disease (SCD) is the most common genetic disorder amongst black people and one of the major chronic non-communicable diseases (NCDs) affecting children, poses a significant psychosocial burden, not only on the sufferers but also on the caregivers and their families. The impact on the family is worse in developing countries such as Nigeria because of inadequate social welfare and health care services. Considering that the overall health of these patients depends on the quality of life and psychological preparedness of the caregivers, an assessment of the burden of the disease on these caregivers and family members is desirable.

They went further to state that the sickle cell disease sufferers as well as their caregivers, are faced with several challenges such as daily use of routine drugs, recurrent or frequent illness, the need for blood transfusion, regular clinic attendance and hospitalization. Hence, parents or caregivers of these children tend to have worse health related quality of life, compared to those without sickle cell disease children which impacts negatively on their behavior and self esteem. The rates of bone pain episodes and hospitalization amongst sickle cell disease children were high, and this account for the reasons why they are admitted in most cases which eventually creates the social as well as the psychological burdens of the disease on the victims, (Adegoke and Kuteyi 2012).

The caregivers sometimes or frequently neglected other members of the family because of the demands caused by the child's illness. It is known that the way parents relate with their ill children and the feelings of neglect this generates in other siblings is a major factor in family dysfunction. This neglect especially when experience too frequently has been described as a risk factor in the psychopathology of psychosocial problems in chronic physical illness.

Frequent school absenteeism as a result of recurrent crises and suboptimal health is another major problem of sickle cell disease children.

On the same issue, Anie et al., (2011) opined that psychosocial issues of people with sickle cell disease and their families mainly result from the impact of pain and symptoms on their daily lives and society's attitude to sickle cell disease and those affected. They went further to say that in Africa, cultural factors are particularly relevant to these problems because of beliefs and traditional practices. In Nigeria, beliefs are usually influenced by cultural and religious values, which influence health behavior such as coping strategies. For example, among the Igbo communities, sickle cell disease is believed to be the result of malevolent. 'Ogbanje' (reincarnation), that is repeated cycles of birth, death and reincarnation. Other studies have shown the religious beliefs play a positive part in coping including prayer, faith in God and Doctors, and hopeful approach to health difficulties in Nigeria. According to the Authors (Anie et al., 2011) previous research also revealed that compared with people with sickle cell disease in the United Kingdom, those in Nigeria commonly used praying and hoping as an affective coping strategy, which seems to be influenced by external factors such as religion, faith in God, superstitions and stigma.

Furthermore, the impact of chronic illness such as sickle cell disease on individuals may be grouped into a set of illness-related-tasks, adjusting to the symptoms and incapacities, maintaining adequate relationships with health care providers, and managing the emotional and social consequences of the illness. Studies on psychosocial aspects of sickle cell disease generally examined the extent of its impact on children and adults, the ways in which affected families function, and the resultant psychological adjustment. Sickle cell disease is a risk factor for maladjustment (Psychosocial functioning) in children and adolescents rates of poor psychological adjustment of children with sickle cell disease remained relatively constant over time. However, there was less stability in child psychological adjustment reported by children as opposed to reports by mothers.

The society's attitude and perceptions had a psychosocial impact on people with sickle cell disease. Health beliefs could be influenced by external factors such as advice given by health workers, family support and work responsibility. Anecdotal evidence suggests teasing and bullying are common complaints among school going children with sickle cell disease. Other major psychosocial problems experienced by young people with sickle cell disease during their school going years have also been described important issues include fear of early death, fears of talking to friends and teachers about the condition, embarrassment about bedwetting and reluctant to take part in school trips because of this teasing by colleagues due to jaundice and associated discoloration of their eyes, and anger should ill-informed staff consider the child as lazy and wanting to keep away from school activities. Anxieties that young people with sickle cell disease experience at school may result in the development of a negative image of themselves, teachers and school staff.

Mood is an important consequence of sickle cell disease people with sickle cell disease commonly low self-esteem and feelings of hopelessness as a result of frequent pain, hospitalizations and loss of schooling (in children) and employment (on adults). These accounts could indicate depressive symptoms; feelings of anxiety and self-hate were uncommon. In Nigeria, most of these people with sickle cell disease were worried and had depressive thought about their condition.

### **Health Related Quality of Life (HRQoL)**

Welkom (2012) and Christopher (2005) were of the opinion that there is a unique interplay between the patient's psychosocial adjustment and the pathophysiology of sickle cell disease. Given the increase in medical advancements and subsequent decreases in disease morbidity and mortality, more attention has focused on Quality of Life (QoL) which is an individual's assessment of his/her satisfaction with various aspects of his/her life (e.g. physical, emotional, school and social) Health Related Quality of Life (HRQoL) refers more specifically to the impact of the child's illness on their subjective well-beings, measuring quality of life has become increasingly important for its function in evaluating interventions, assessing prognostic factors, comparing therapies, and allocating resources.

Children with sickle cell disease were experiencing more psychosocial maladjustment compared to the healthy controls. Moreover, children with sickle cell disease has significantly more limited general health and physical functioning, more limitations in their academic functioning and social activities attributed to their physical health and more behavior and emotional problems when compared to a healthy control group. Moreover in an adult sickle cell disease population, research has shown that the frequency of sickle cell pain episodes over a 12 month period was associated with impairment of quality of life.

Monika (2008) stated that in assessing the seriousness of this disease (SCD) no one should underestimate its emotional and social impact. The patient endures not only the pain itself but also the emotional strain from unpredictable bouts of pain, fear of death, and lost time and social isolation at school and work. It is also known that psychological and social factors contribute substantially to complaints of pain.

### **Psychosocial Impacts of Sickle Cell Disease on The Families of The Victims**

According to Xandra (2008) caring for a child with sickle cell disease poses extra demands on parents, both practically and psychologically, which may influence their quality of life. Since families of children with sickle cell disease in the Netherlands usually belong to immigrant communities with a low socio-economic status, there may be an additional strain on caregivers.

Furthermore, the quality of care they receive may be affected by the caregivers' well-being. The unpredictable course of sickle cell disease in combination with the lower socio-economic status (SES) of most caregivers places a heavy strain on the caregivers of these children. The challenge of parenting a child with sickle cell disease has been described as a burden. This burden can be classified as objective and subjective.

The objective burden includes day to day management of the illness, the effect on other aspects of life and financial consequences. Caregivers of children with sickle cell have to administer medication daily (e.g. antibiotics prophylaxis and folic acid), promote behavior that minimized pain episodes and act appropriately when symptoms arise by giving scheduled analgesics and plenty of fluids in the case of a painful crises. Vaso occlusive crises and hospital visits interfere with work commitments and planned (leisure) activities of caregivers and other family members. Financial consequences may arise as a result of travel expenses for trips to the hospital and a poor health status of a child has been associated with reduced maternal or paternal employment.

The emotional distress caregivers experience when dealing with their ill child can be classified as a subjective burden. Confronting the pain of their child during vaso-occlusive crises is

emotionally upsetting from parents. Caregivers may have difficulty accepting the child's diagnosis and prognosis and may experience anxiety about the child's future well being both in short and long term. Also from the opinion of Adegoke and Kuteyi (2012), the financial burden of sickle cell disease on the caregivers and their families is high. i.e. the expenses of the child's illness adversely affected the family's basic needs such as food and house rent. This is not surprising considering the rising trend of inflation in the period of global economic recession and socio-political instability. In Nigeria, like many other developing countries, national programmes on health insurance and social welfare systems are absent, making caring for a child with chronic illness such as sickle cell disease great financial burden.

From the same studies, Adegoke and Kuteyi (2012) claimed that about 70% of the caregivers lost income or financial benefits due to time spent caring for their children. In Nigeria, the predominant form of health care financing is out-of-pocket. As observed previously above, job loss, under employment and/or unemployment arising from time spent caring for a child with sickle cell disease will significantly contribute to the financial burden experienced by caregivers and their family.

From the view point of Tunde-Ayinmode (2008), tripartite interaction between the patient, their disease and their social environment including the family is dynamic and fraught with risks of maladjustment. Chronic physical illness are known to provoke psychosocial dysfunction in affected children and their families. Some factors recognized as mediating psychosocial dysfunction in physical illness include: nature and severity of disability caused by the disease, mode of management and degree of social restriction imposed by the disease on the patient and their family childhood physical illness impacts greatly on family functioning by virtue of its central role as a socializing agent, the structure and functioning state of the family can affect and be affected by a child's physical illness.

Mothers more often accompany their children to the clinics than fathers' and are therefore in a position to give a better description of the burden of the illness on their families. By virtue of these roles, mothers are likely going to bear a substantial portion of the psychosocial impact of the disease on the family.

When an individual behaves in a way to change an impact he may simultaneously create another e.g. the taking on of extra work by mother of a sickle cell disease child to reduce the financial burden of sickle cell disease, may mean an increased risk of physical, social and emotional neglect of her family with consequent marital disharmony. Psychosocial impact is considered an issue because it may cause significant distress.

In addition to these social complications, the psychological burden for affected parents could also be substantial anger, grief, depression, resentment, guilt and fear of early death of life.

### **Treatment strategies for sickle cell disease and remedies of ameliorating the incidence of the condition in our society**

According to Bras (2011) on the above subject matter, the benefits of early diagnosis and intervention in the monitoring of sickle cell disease have led to wide spread use of education program to detect these conditions. Through neonatal screening programs, it is possible to reduce morbidity and mortality in the first five years of life.

Furthermore, the prophylactic use of penicillin, the administration of pneumococcal vaccine and intensive care significantly increase the survival and quality of life of patients with sickle

cell disease, reducing and extenuating the consequences of clinical complications. Bras went further to state that in 1986, one of the first Brazilian studies was published demonstrating the importance of detecting haemoglobin diseases early through a study that analyses blood sample from the umbilical cord by means of electrophoresis in starch agar gel.

The study tested 2281 samples, 78 of which had abnormal haemoglobins with preponderance among children from black mothers. In addition, it was shown that haemoglobin S represented 80.8% of abnormal samples, thereby providing the importance of neonatal screening for the detection of the alteration. In 2001, the Ministry of Health included testing for haemoglobinopathies in the National Neonatal Screening Programme (PNTN) through Decree No 822101. Thus all children who are submitted to the Guthrie test in Brazilian state after completing implementation phases II and III of the Neonatal Screening Programme are also screened for haemoglobinopathies, in particular sickle cell anaemia, in order to provide an early diagnosis.

Adegoke and Kuteyi (2012) claimed that within the family micro-environment, children with sickle cell disease need optimal family support, understanding and care, particularly in terms of providing adequate nutrition and health care delivery so as to achieve an optimum and steady state of health. Such favourable family environment has been shown to be a good prognostic index. WHO (2014), said presently there is no cure for sickle cell disease. However, cost effective treatment exists for the pain and other aspects of the disease. The most important components of this treatment are early intervention with analgesics, antibiotics, rest, good nutrition, folic acid supplementation and high fluid intake. At times, invasive procedures such as blood transfusion and surgery may be needed.

Research in some countries in the region (Benin, Burkina Faso, Nigeria, Togo) has yielded therapeutic agents effective in preventing or reducing the frequency and severity of crises. There is sufficient evidence that neonatal screening for sickle cell disease, when linked to timely diagnostic testing, parental education and comprehensive care, markedly reduced morbidity and mortality in infancy and early childhood. Nevertheless, simple, in expensive and cost effective procedures such as the use of penicillin to prevent infections are not available to most patients WHO (2014). In the same vein, John (2009) is of the opinion that early diagnosis of sickle cell disease is very important because many complications can be prevented with early diagnosis and treatment. In the United States, all state governments require testing for sickle cell disease as part of their new born screening programs. The test uses blood from the blood samples used for other routine newborn screening tests. It can show whether a new born infant has sickle cell disease or sickle cell trait. If the test shows sickle cell haemoglobin, a second blood test is done to confirm the diagnosis.

It's also possible for doctors to diagnose sickle cell disease before birth. This is done using a sample of amniotic fluid or tissues taken from the placenta. This test can be done in the first few weeks of pregnancy. The goals of treating sickle cell disease are to prevent or relieve pain, prevent infections, organ damage, and strokes, treat anaemia and control complications.

- **Treating Pain:** Mild pain is often treated with over-the counter medicine and heating pads. Severe pain may need to be treated in a hospital. The usual treatment for acute (short-term) pain are fluids and pain controlling medicines.

Fluids help prevent dehydration, a condition in which the body doesn't have enough fluid. Fluids are given either by mouth or through a vein. Common medicines used to treat pain crises include acetaminophen, non-steroidal anti-inflammatory drugs (NSAIDs) and

narcotics. Treatment for mild to moderate pain usually begins with NSAIDS or acetaminophen, John (2009).

- **Preventing Pain:** Those with more severe sickle cell anaemia may benefit from daily administration of a medicine called hydroxyurea. This medicine may help reduce the number of painful crises. Hydroxyurea is used to prevent painful crises, not to treat them when they occur. This is achieved in part by reactivating foetal haemoglobin production in place of the haemoglobins that causes sickle cell anaemia, John (2009).
- **Preventing Infection:** Bacterial infections can be a major complication of sickle cell disease, but often they can be prevented or treated. If a child who has sickle cell disease shows early signs of an infection, such as a fever, difficulty treating or localized bone pain treatment should be given right away. To prevent infection in babies and young children, treatment include:

*Daily Dose of Penicillin:* Treatment may begin as early as two (2) months of age and continue until the child is at least five (5) years old, John (2009).

**All Routine Vaccinations:** (Including a yearly flu shot) plus vaccination(s) against streptococcus pneumonia, adult who have sickle cell disease should receive flu shots every year and get vaccinated against pneumococcal infections.

### **Transfusion Therapy**

Blood transfusions are often used in the management of sickle cell disease in acute cases and to prevent complications by decreasing the number of red blood cells that can sickle by adding normal red blood cells. In children prophylactic chronic red blood cell transfusion therapy has been shown to be efficacious to a certain extent in reducing the risk of first stroke or silent stroke when transcranial.

### **Bone Marrow Transplant**

Bone marrow transplants can cure sickle cell disease because the procedure has significant risks, transplants are not appropriate for every patient. Bone marrow transplants are used primarily in young patients who have severe sickle cell disease. However, the decision to give this treatment is made on a case-by-case basis. Bone marrow used for a transplant must come from a closely matched donor. This is usually a close family member who doesn't have sickle cell diseases.

### **Gene Therapy**

Scientists are studying gene therapy as a possible treatment for sickle cell disease. Researchers want to know whether a normal gene can be put in the bone marrow of a person who has sickle cell disease. This would cause the body to make normal red blood cells. Researchers also are studying whether they can

Turn off the sickle cell gene or 'turn on' a gene that makes red blood cells behave more normally.

## **New Medicines**

Researchers are studying several new medicines for sickle cell anaemia, some of these interfere with sickling of haemoglobin, others prevent the cells from sticking to blood vessel walls and some raise levels of the haemoglobin present before birth-fetal haemoglobin. Adegoke and Kuteyi (2012) also opined that social welfare programmes such as national health insurance for children with chronic illness will definitely alleviate the associated financial burden. For instance, the caregivers of sickle cell disease children in Western Countries such as the United Kingdom have the opportunity to benefit from health insurance and hence, they tend to report lower financial burdens compared with their counterparts in most parts of the developing world. Other social welfare programmes and self-help group programs are also vital in relieving the psychosocial burden of disease and consequently, improving the quality of care for the sickle cell disease patients, presently in Nigeria, the National Sickle Cell Association and sickle Disease Clubs are based in a few tertiary health institutions with insufficient community impact. These social organizations should be encouraged so that sickle cell disease children and their caregivers can share their feelings and counsel one another. Other measures to reduce the impact of sickle cell disease on caregivers include limitation of family size to reduce the risk of mothers from having additional sickle cell disease children. In addition, there should be promotion of neonatal screening, genetic counseling and comprehensive public health education. The latter must aim at increasing community awareness on the burden and prevention of the disease. Routine haemoglobin genotype determination for adolescents before entering into marital relationships is vital. This has been noted to offer a pragmatic approach in reducing the high prevalence of the sickle cell gene and the attendant problems in Nigeria.

On the same note, WHO (2014) noted that creation or strengthening of national sickle cell disease control programmes within the framework of national programmes for prevention and control of non-communicable disease is necessary in affected countries. Essential areas of work should cover advocacy, prevention and counseling, early detection and treatment, data collection, surveillance and research and community education and partnerships. A multidisciplinary team involving health and social workers, teachers' parents and concerned non-governmental organizations could be established to work on the practical aspects of implementation and monitoring of the programme. Prevention entails setting up sickle cell screening and genetic counseling programmes in high prevalence countries. Ideally, the disease should be identified during the prenatal period or at birth as part of a routine screening programme. Such services should be available alongside counseling and health education services since diagnosis raises serious ethical and cultural issues which differ from one country to another. Genetic counseling and screening can lead to substantial reduction in the number of children born with the trait.

Management of sickle cell disease at different levels of the healthcare system should emphasize programmes that use simple, affordable technology and are accessible to a large proportion of the community. Such programmes are preferred instead of a parallel system which may be too expensive and unsustainable. The programme should be developed at the primary care level with appropriate technical and patient referral support from higher levels of care. Training of health personnel on prevention, diagnosis and case management should ensure that the health care system is able to provide the basic requirements of these services. Family and community-based care should be an integral part of the national programme.

Surveillance and research are important components of the programme. The information generated should be disseminated and used as evidence in policy-making as well as in day-to-



day decision-making in the management of the programme. It is also necessary to study the natural history of the disease and its effects on clinical manifestations and transmission of malaria.

Partnerships should be fostered between health professionals, parents, patients, relevant community interested groups and the media, where appropriate, partnerships will facilitate public education, identification of genetic risks in the community by recording family disease histories, genetic counselling awareness and advice participation in prevention and care programmes.

### **Research Design**

This study design is a descriptive one. This design was adopted since the researcher did not manipulate any of the variable but variables were described as occurred in the study.

### **Research Settings**

This research study was conducted in Ogbomoso North Local Government Area in Oyo State. Ogbomoso is a city in Oyo State, South-western Nigeria, A1 highway. It was founded in the mid 17<sup>th</sup> century. Ogbomoso North is a Local Government Area in Oyo State, Nigeria. Its headquarter is in Ogbomoso and currently headed by Caretaker Chairman until Local Government Chairman Poll is held. The Local Government serves as a home to one of Nigeria's best institution of learning, Ladoke Akintola University of Technology (LAUTECH) and its teaching hospital.

Also, Baptist Medical Centre (Bowen University Teaching Hospital) is situated there. The SOUN palace is the major traditional home of the town. Ogbomoso North is the largest local government in the city, being the city's major economic nerve. It is the most populous local government in the city as at 2006 census. The population of Ogbomoso land as of 2006 was around 1,200,000 while that of Ogbomoso North Local Government Area was 198,859. There are 10 wards in Ogbomoso North Local Government Area. Aaje Ogunbado/Oke Agbede, Abogunde, Aguodo/Masifa, Isale Afon, Isale Alaasa, Isale Ora/Saja, Jagun, Okelerin, Osupa, Sabo/Tara.

The postal code of the area is 201. Ogbomoso north local government was established on the 29<sup>th</sup> September, 1991 by the former president and chief of the armed forces Federal Republic of Nigeria, General Ibrahim Gbadamosi Babangida during the military era. It is said to be the cradle of the four local government councils in Ogbomoso metropolis. Southern part is bordered by Ogbomoso South Local Government, Eastern part is boarded by Surulere Local Government Area and Western part is Oriire Local Government Area. There are Twenty-five primary schools, pone rehabilitation centre for virtually handicapped children there are five secondary schools and many private secondary schools.

### **Study Population**

The study population for/of the study will composed of males and females of people living with sickle cell disease from some selected hospitals in Ogbomosho, LAUTECH Staff Clinic, some selected secondary schools together with some religious institutions in Ogbomoso. They would be considered for the study because they are within the age bracket of thirteen and above (13 and above) years.

**Inclusion Criteria**

The subjects or participants for the study will compose of males and females suffering from sickle cell disease within the age range of thirteen and 40+ (13 and 40+) years due to the fact that they would be able to read and write if given open ended questionnaire to fill or complete, besides they would be able to express themselves well/fluently when interviewed orally, while the illiterates among them would be able to express themselves well whole interviewed orally.

**Exclusion Criteria**

Sickle cell children that are below thirteen years of age would be excluded from the research study due to the fact that children within this age bracket would neither be able to read and write when given open ended questionnaire to complete nor able to express themselves well when interviewed. Likewise those that are not living with sickle cell disease (SCD).

**Sampling Technique and Sample Size Determination**

The method used was snow ball method whereby the participant are selected by non random methods, this involve choosing the most conveniently available people as study participants without being coerced i.e. they agree to participate in the study/exercise voluntarily.

**Sample Size Determination**

The sample size comprised of eighty (80) males and females of people living with sickle cell disease selected from some selected hospitals running sickle cell disease clinic, LAUTECH Staff Clinic, some selected secondary schools together with some religious institutions such as churches and mosques all located in Ogbomoso North Local Government.

**Sample size determination**

Yamane

$$n = \frac{n}{1+N} (0.05)^2$$

where:

n = sample size when population is >10,000 = 400

N = target population

1 = constant

N = 400

$$\frac{400}{1 + (400 \times 0.05)^2}$$

$$1 + (400 \times 0.05)^2$$

n = 400/2 = 200. However, because of the nature of the respondent, the sampling element was used.

### **Instrument for Data Collection**

The research instruments were four (4) folds

Section A was a self designed demographic variables of correspondents and consisted of 6 items.

Section B was equally researcher's self designed instrument on knowledge of causes of sickle cell disease.

Section C was on psychosocial impact which was adapted from Hamilton anxiety scale and consisted of 10 items and the last was Section D was on productive coping styles which was adapted from Jan samples productive coping styles and consisted of 10 items.

### **Methods of Data Analysis**

The analysis of the data collected is done using descriptive analytical interpretations to communicate the findings of the research. The data obtained was thoroughly scrutinized and articulately presented for a better understanding of the psychosocial impact of sickle cell disease of people living with the disease. The data obtained through interviews, focus group discussion are from other sources assisted to increase our awareness on the psychosocial impact of sickle cell disease.

### **Ethical Consideration**

The researcher will visit the selected hospitals, LAUTECH Staff Clinic, selected secondary schools together with some selected religious institutions, permission of the appropriate authorities of the selected institutions was sought as well as the voluntary consents of the participants/subjects, and they were informed about the nature of the study. The rights of the participants or respondents to privacy, confidentiality and dignity remained intact throughout the course of the investigation and afterwards.

## **RESULT**

This section covered the presentation of data, answering of research questions, testing of hypotheses and discussion of findings. It was in this section the variables of interest were analyses for good inferences upon which valid decisions were made for good recommendations.

**ANSWERING OF RESEARCH QUESTIONS****Research question 1****Table 1: What are the demographic characteristics of the respondents?**

<b>GENDER</b>	<b>FREQUENCY</b>	<b>%</b>
Non Response	4	5.1
Male	39	49.4
Female	36	45.6
Total	79	100
<b>AGE</b>	<b>FREQUENCY</b>	<b>%</b>
No Response	1	1.3
13-20	54	68.4
21-30	18	22.8
31-40	3	3.8
41 and above	3	3.8
Total	79	100
<b>ETHNIC GROUP</b>	<b>FREQUENCY</b>	<b>%</b>
No Response	1	1.3
Yoruba	76	96.2
Igbo	2	2.5
Total	79	100
<b>LOCAL GOVERNMENT AREA</b>	<b>FREQUENCY</b>	<b>%</b>
OSLE	13	16.5
ONLG	48	60.8
ORIRE	2	2.5
SURULERE	10	12.7
EJIGBO WEST	2	2.5
OGOOLUWA	1	1.3
NORTH EAST	1	1.3
ORIOWO LG	1	1.3
OYO EAST	1	1.3
Total	79	100
<b>LIVING STATUS</b>	<b>FREQUENCY</b>	<b>%</b>
Alone	15	19
With Spouse/Partner	4	5.1
With Parents	60	75.9
Total	79	100
<b>MARITAL STATUS</b>	<b>FREQUENCY</b>	<b>%</b>
Single	70	88.6
Separated	2	2.5
Married	7	8.9
Total	79	100
<b>RELIGION</b>	<b>FREQUENCY</b>	<b>%</b>
Non Response	1	1.3
Christianity	57	72.2
Islam	21	26.6
Total	79	100

Table 1 above shows the demographic characteristics of the Respondents. 49.4% (39) of the respondents were Male, 45.6% (36) were Female while 5.1% (4) gave no response on their

gender. 68.4% (54) of the respondents were between the age of 13-20 years, 22.8% (18) were between the age of 21-30 years, 3.8% (3) were between the age of 31-40 years, 3.8% (3) were 40 years and above while 1.3% (1) of the respondents gave no response on their age group. Based on their ethnic group, 1.3% (1) gave no response, 96.2% (76) were Yoruba while 2.5% (2) were Igbo. In respect to the local government area each respondents was from, 16.5% (13) of the target population were from Ogbomoso South Local Government (OSLG), 60.8% (48) were from Ogbomoso North Local Government (ONLG), 2.5% (2) were from Oriire Local Government, 12.7% (10) were from Surulere Local Government, 2.5% (2) were from Ejibo West Local Government, 1.3% (1) was from Ogooluwa Local Government, 1.3% (1) was from North East Local Government, 1.3% (1) was from Oriowo Local Government while 1.3% (1) of the respondents was from Oyo East Local Government. 19% (15) of the target population were living alone, 5.1% (4) were living with their spouse/partner while 75.9% (60) were living with parents. 88.6% (70) of the respondents were single, 2.5% (2) were separated and 8.9% (7) were married. Based on their Religion, 72.2% (57) were into Christianity, 26.6% (21) were into Islam while 1.3% (1) gave no response.

## Research question 2

**Table 2: What does the term sickle cell disease imply among the respondents?**

<b>What does the term sickle cell disease mean?</b>	<b>Frequency</b>	<b>%</b>
No response	2	2.5
Sickle cell disease is a hereditary blood disorder characterized by an abnormality in the oxygen-carrying haemoglobin molecules in red blood cells	9	11.4
A condition which occurs when a person inherits two abnormal copies of the haemoglobin gene	6	7.6
A condition that leads to a propensity for the cell to assume an abnormal rigid sickle cell like shape	1	1.3
all of the above	61	77.2
Total	79	100
<b>The mode of getting sickle cell disease is when a person inherits two abnormal copies of the haemoglobin gene?</b>	<b>Frequency</b>	<b>%</b>
Non Response	3	3.8
Yes	76	96.2
Total	79	100
<b>Sickle cell disease affects all age groups and both sexes</b>	<b>Frequency</b>	<b>%</b>
Non Response	4	5.1
Yes	75	94.9
Total	79	100
<b>Couple with sickle cell trait is at risk of having sickle child/children</b>	<b>Frequency</b>	<b>%</b>
Non Response	6	7.6
Yes	73	92.4
Total	79	100
<b>A person with a single abnormal copy does not experience symptoms and is said to have sickle cell trait</b>	<b>Frequency</b>	<b>%</b>
Non Response	4	5.1
Yes	75	94.9
Total	79	100

The above table 2 indicated what the term sickle cell disease implies among the respondents. 11.4% (9) of the respondents agreed that sickle cell disease is a hereditary blood disorder characterized by abnormality in the oxygen-carrying haemoglobin molecules in red blood cells, 7.6% (6) said that sickle cell disease is a condition which occurs when a person inherits two abnormal copies of the haemoglobin gene, 1.3% (1) agree that sickle cell disease is a condition that leads to a propensity for the cell to assume an abnormal rigid sickle cell like shape, 77.2% (61) agreed to all the terms while 2.5% (2) gave no response. 96.2% (76) of the target population agreed that the mode of getting sickle cell disease is when a person inherits two abnormal copies of the haemoglobin gene while 3.8% (3) gave no response. 94.9% (75) of the respondents agreed that sickle cell disease affects all age groups and both sexes while 5.1% (4) gave no response. 92.4% (73) agreed that couple with sickle cell trait is at risk of having sickle child/children while 7.6% (6) gave no response, 94.9% (75) of the target population agree that a person with a single abnormal copy does not experience symptoms and is said to have sickle cell trait while 5.1% (4) gave no response.

### Research question 3

**Table 3: What are the psychosocial impacts among people living with sickle cell disease?**

Parameters	Not present	Mild	Moderate	Severe	Very severe
Anxious mood	23(29.1%)	20(25.3%)	24(30.4%)	9(11.4%)	3(3.8%)
Tension	20(25.35)	24(30.4%)	23(29.1%)	7(8.9%)	5(6.3%)
Fears	15(34.2%)	23(29.1%)	26(32.9%)	9(11.4%)	6(7.6%)
Insomnia	27(34.2%)	19(24.1%)	23(29.1%)	7(8.9%)	3(3.8%)
Intellectual	19(24.1%)	18(22.8%)	36(45.6%)	0	6(7.6%)
Depressed mood	24(30.4%)	28(35.4%)	14(17.7%)	9(11.4%)	4(5.1%)
Somatic (muscular)	19(24.1%)	18(22.8%)	24(30.4%)	10(12.7%)	8(10.1%)
Somatic (sensory)	25(31.6%)	15(19%)	28(32.9%)	4(5.1%)	9(11.4%)
Cardiovascular symptoms	41(51.9%)	21(26.6%)	12(15.2%)	4(5.1%)	1(1.3%)
Respiratory symptoms	39(49.4%)	27(34.2%)	9(11.2%)	2(2.5%)	2(2.5%)
Gastrointestinal symptoms	42(53.2%)	19(24.1%)	15(19%)	2(2.5%)	1(1.3%)
Genitourinary symptoms	49(62%)	17(21.5%)	11(13.9%)		2(2.5%)
Autonomic symptoms	35(44.3%)	31(39.2%)	11(13.9%)	2(2.5%)	
Behavior at interview	28(35.4%)	22(27.8%)	20(25.3%)	6(7.6%)	3(3.8%)
Financial incapacitation	30(38%)	15(19%)	25(31.6%)	5(6.3%)	4(5.1%)
Family disharmony	56(70.9%)	10(12.7%)	11(13.9)		2(2.5%)
Peer group isolation	40(50.6%)	17(21.5%)	15(19%)	2(2.5%)	5(6.3%)
	<b>39.62%</b>	<b>25.62%</b>	<b>24.18%</b>	<b>5.81%</b>	<b>4.76%</b>

The psychosocial impacts among people living with sickle cell disease were shown in table 3 above. 29.1% (23) of the respondents agreed that Anxious mood is not present, 25.3% (20) agreed that Anxious mood is mild, 30.4% (24) said it is moderate, 11.4% (9) agreed that it is severe while 3.8% (3) agreed that Anxious mood is very severe among people living with sickle cell disease. As for tension as a psychosocial impact among sickle cell disease people, 25.3% (20) agreed that it is not present, 30.4% (24) agreed that it is mild, 29.1% (23) agreed that it is

moderate, 8.9% (7) agreed that it is severe while 6.3% (5) of the respondents agreed that it is very severe. As for fear, 19% (15) of the respondents agreed that it is not present, 29.1% (23) agreed that it is mild, 32.9% (26) agreed that it is moderate, 11.4% (9) agreed that it is severe while 7.6% (6) of the respondents agreed that it is very severe among people living with sickle cell disease. 34.2% (27) of the target population said that Insomnia is not present, 24.1% (19) agreed that Insomnia is mild, 29.1% (23) said it is moderate, 8.9% (7) said it is severe while 3.8% (3) agreed that Insomnia is very difficult among sickle cell disease people. As for intellectual as a psychosocial impact among people with sickle cell disease, 24.1% (19) of the respondents agreed that it is not present, 22.8% (18) agreed that it is mild, 45.6% (36) agreed that it is moderate while 7.6% (6) said it is very severe. 30.4% (24) of the respondents agreed that Depressed mood is not present, 35.4% (28) agreed that Depressed mood is mild, 17.7% (14) said it is moderate, 11.4% (9) agreed that it is severe while 5.1% (4) agreed that Depressed mood is very severe among people living with sickle cell disease. As for somatic (muscular) as a psychosocial impact among sickle cell disease people, 24.1% (19) agreed that it is not present, 22.8% (18) agreed that it is mild, 30.4% (24) agreed that it is moderate, 12.7% (10) agreed that it is severe while 10.1% (8) of the respondents agreed that it is very severe. As for somatic (sensory) 31.6% (25) of the respondents agreed that it is not present, 19% (15) agreed that it is mild, 32.9% (28) agreed that it is moderate, 5.1% (4) agreed that it is severe while 11.4% (9) of the respondents agreed that it is very severe among people living with sickle cell disease. 51.9% (41) of the target population said that cardiovascular symptoms is not present, 26.6% (21) agreed that it is mild, 15.2% (12) said it is moderate, 5.1% (4) said it is severe while 1.3% (1) agreed that cardiovascular symptoms is very difficult among sickle cell disease people. As for Respiratory symptoms as a psychosocial impact among people with sickle cell disease, 49.4% (39) of the respondents agreed that it is not present, 34.2% (27) agreed that it is mild, 11.2% (9) agreed that it is moderate, 2.5% (2) agreed that it is severe while 2.5% (2) said it is very severe. 53.2% (42) of the respondents agreed that Gastrointestinal symptoms is not present, 24.1% (19) agreed that it is mild, 19% (15) said it is moderate, 2.5% (2) agreed that it is severe while 1.3% (1) agreed that it is very severe among people living with sickle cell disease. As for Genitourinary symptoms as a psychosocial impact among sickle cell disease people, 62% (49) agreed that it is not present, 21.5% (17) agreed that it is mild, 13.9% (11) agreed that it is moderate while 2.5% (2) of the respondents agreed that it is very severe. As for Autonomic symptoms, 44.3% (35) of the respondents agreed that it is not present, 39.2% (31) agreed that it is mild, 13.9% (11) agreed that it is moderate while 2.5% (2) agreed that it is severe among people living with sickle cell disease. 35.4% (28) of the target population said that Behaviour at Interview is mild, 25.3% (20) said it is moderate, 7.6% (6) said it is severe while 3.8% (3) agreed that it is very difficult among sickle cell disease people. As for Financial incapacitation as a psychosocial impact among people with sickle cell disease, 38% (30) of the respondents agreed that it is not present, 19% (15) agreed that it is mild, 31.6% (25) agreed that it is moderate, 6.3% (5) agreed that it is severe while 5.1% (4) said it is very severe. 70.9% (56) of the respondents agreed that Family disharmony as a psychosocial impact on sickle cell disease people is not present, 12.7% (10) agreed that it is mild, 13.9% (11) agreed that it is moderate while 2.5% (2) agreed it is severe in people with sickle cell disease. Lastly, 50.6% (40) of the target population agreed that Peer Group Isolation is not present in people with sickle cell disease, 21.5% (17) agreed that it is mild, 19% (15) agreed that it is severe while 6.3% (5) agreed that Peer group isolation as a psychosocial impact is very severe in people with sickle cell disease. A total of 39.2% agreed that all the listed psychosocial impact is not present in people with sickle cell disease, 25.62% agreed that the above psychosocial impact is mild in people with sickle cell disease, 24.18% of the respondents agreed that above psychosocial impacts is moderate in sickle cell disease people, 5.81% agreed that the impact

on people with sickle cell disease is severe while 4.76% of the target population agreed that above psychosocial impact on people with sickle cell disease is very severe.

#### Research question 4

**Table 4: What are the psychosocial effects of sickle cell disease on careers?**

Parameters	Not present	Mild	Moderate	Severe	Very severe
Depressed mood	24(30.4%)	28(35.4%)	14(17.7%)	9(11.4%)	4(5.1%)
Cardiovascular symptoms	41(51.9%)	21(26.6%)	12(15.2%)	4(5.1%)	1(1.3%)
Respiratory symptoms	39(49.4%)	27(34.2%)	9(11.2%)	2(2.5%)	2(2.5%)
Gastrointestinal symptoms	42(53.2%)	19(24.1%)	15(19%)	2(2.5%)	1(1.3%)
Financial incapacitation	30(38%)	15(19%)	25(31.6%)	5(6.3%)	4(5.1%)
Family disharmony	56(70.9%)	10(12.7%)	11(13.9%)		2(2.5%)
Peer group isolation	40(50.6%)	17(21.5%)	15(19%)	2(2.5%)	5(6.3%)
<b>Average %</b>	<b>49.2%</b>	<b>24.79%</b>	<b>18.2%</b>	<b>4.3%</b>	<b>3.44%</b>

The psychosocial effects among people living with sickle cell disease were shown in table 4 above. 30.4% (24) of the respondents agreed that Depressed mood is not present, 35.4% (28) agreed that Depressed mood is mild, 17.7% (14) said it is moderate, 11.4% (9) agreed that it is severe while 5.1% (4) agreed that Depressed mood is very severe among people living with sickle cell disease. 51.9% (41) of the target population said that cardiovascular symptoms is not present, 26.6% (21) agreed that it is mild, 15.2% (12) said it is moderate, 5.1% (4) said it is severe while 1.3% (1) agreed that cardiovascular symptoms is very difficult among sickle cell disease people. As for Respiratory symptoms as a psychosocial impact among people with sickle cell disease, 49.4% (39) of the respondents agreed that it is not present, 34.2% (27) agreed that it is mild, 11.2% (9) agreed that it is moderate, 2.5% (2) agreed that it is severe while 2.5% (2) said it is very severe. 53.2% (42) of the respondents agreed that Gastrointestinal symptoms is not present, 24.1% (19) agreed that it is mild, 19% (15) said it is moderate, 2.5% (2) agreed that it is severe while 1.3% (1) agreed that it is very severe among people living with sickle cell disease. As for Financial incapacitation as a psychosocial impact among people with sickle cell disease, 38% (30) of the respondents agreed that it is not present, 19% (15) agreed that it is mild, 31.6% (25) agreed that it is moderate, 6.3% (5) agreed that it is severe while 5.1% (4) said it is very severe. 70.9% (56) of the respondents agreed that Family disharmony as a psychosocial impact on sickle cell disease people is not present, 12.7% (10) agreed that it is mild, 13.9% (11) agreed that it is moderate while 2.5% (2) agreed it is severe in people with sickle cell disease. Lastly, 50.6% (40) of the target population agreed that Peer Group Isolation is not present in people with sickle cell disease, 21.5% (17) agreed that it is mild, 19% (15) agreed that it is severe while 6.3% (5) agreed that Peer group isolation as a psychosocial impact is very severe in people with sickle cell disease. A total of 49.2% agreed that all the listed psychosocial effects is not present in people with sickle cell disease, 24.79% agreed that the above psychosocial effects is mild in people with sickle cell disease, 18.2% of the respondents agreed that above psychosocial effects is moderate in sickle cell disease people, 4.3% agreed that the impact on people with sickle cell disease is severe while 3.44% of the target population agreed that above psychosocial effects on people with sickle cell disease is very severe.



**Research question 5****Table 5: What are the specific coping strategies being adopted by people living with sickle cell disease?**

<b>Parameters</b>	<b>Never</b>	<b>Seldom</b>	<b>Sometimes</b>	<b>Often</b>	<b>Very Often</b>
Sharing the problem with other and enlisting support in its management	28(35.4%)	12(15.2%)	25(31.6%)	6(7.6%)	8(10.1%)
Reflecting on the problem, planning solutions and tackling the problem systematically	11(13.9%)	14(17.7%)	24(30.4%)	23(29.1%)	7(8.9%)
Playing sport and keeping fit	14(17.7%)	16(20.3%)	31(39.2%)	13(16.5%)	5(6.3%)
Engaging in general leisure activities not sport either alone or with others	5(6.3%)	18(22.8%)	28(35.4%)	26(32.9%)	2(2.5%)
Engaging in a particular intimate	12(15.2%)	10(12.7%)	29(36.7%)	18(22.8%)	10(12.7%)
Having commitment, ambition and industry	10(12.7%)	14(17.7%)	16(20.3%)	24(30.4%)	15(19%)
Maintaining a positive and cheerful outlook on the current situation	4(5.1%)	16(20.3%)	24(30.4%)	22(27.8%)	13(16.5%)
Accepting one's best efforts and that there is nothing further to be done	26(32.9%)	18(22.8%)	15(19%)	13(16.5%)	7(8.9%)
Letting others know what is of concern and enlisting support by organizing on activity	20(25.3%)	19(24.1%)	24(30.4%)	9(11.4%)	7(8.9%)
Using a professional adviser, such as counselor	10(12.7%)	10(12.7%)	14(17.7%)	25(31.6%)	20(25.3%)
<b>Average %</b>	<b>17.72%</b>	<b>18.63%</b>	<b>29.11%</b>	<b>22.66%</b>	<b>11.91%</b>

The table 5 above shows the specific coping strategies adopted by people living with sickle cell disease. 35.4% (28) agreed that sharing the problem with others and enlisting support in its management was never a coping strategy adopted by people living with sickle cell disease, 15.2% (12) seldom sharing the problem with others and enlisting support in its management, 31.6% (25) agreed that people with sickle cell disease sometimes share the problem with others and enlisting support in its management, 7.6% (6) agreed that they often sharing the problem with others and enlisting support in its management while 10.1% (8) agreed that they sharing the problem with others and enlisting support in its management very often. 13.9% (11) of the respondents said people with sickle cell disease never reflect on the problem, plan solutions and tackle the problem systematically, 17.7% (14) said they seldom reflect on the problem,

plan solutions and tackle the problem systematically, 30.4% (24) of the respondents said people with sickle cell disease sometimes reflect on the problem, plan solutions and tackle the problem systematically, 29.1% (23) said sickle cell disease people often reflect on the problem, plan solutions and tackle the problem systematically while reflecting on the problem, plan solutions and tackle the problem systematically was adopted very often by people with sickle cell disease as agreed by 8.9% (7) of the respondents. 17.7% (14) said sickle cell disease people never engage in playing sport and keeping fit, 39.2% (16) said sickle cell disease seldom play sport and keeping fit, 16.5% (13) agreed that they often play sport and keeping fit while 6.3% (5) agreed that playing sport and keeping fit was adopted very often by sickle cell disease people. 6.3% (5) agreed that engaging in general leisure activities not sport either alone or with others was never a coping strategy adopted by people living with sickle cell disease, 22.8% (18) agreed that they seldom engage in general leisure activities not sport either alone or with others, 35.4% (28) agreed that people with sickle cell disease sometimes engage in general leisure activities not sport either alone or with others, 32.9% (26) agreed that they often engage in general leisure activities not sport either alone or with others while 2.5% (2) agreed that they engage in general leisure activities not sport either alone or with others very often. 15.2% (12) agreed that engaging in a particular intimate relationship was never a coping strategy adopted by people living with sickle cell disease, 12.7% (10) agreed that they seldom engage in a particular intimate relationship, 36.7% (29) agreed that people with sickle cell disease sometimes engage in a particular intimate relationship, 22.8% (18) agreed that they often engage in a particular intimate relationship while 12.7% (10) agreed that they engage in a particular intimate relationship. 12.7% (10) of the respondents said people with sickle cell disease never have commitment, ambition and industry, 20.3% (16) of the respondents said people with sickle cell disease sometimes have commitment, ambition and industry, 17.7% (14) said they seldom have commitment, ambition and industry, 20.3% (16) said people with sickle cell disease sometimes have commitment, ambition and industry, 30.4% (24) said they often have commitment, ambition and industry while having commitment, ambition and industry was adopted very often by people with sickle cell disease as agreed by 8.9% (7) of the respondents. 5.1% (4) said sickle cell disease people never maintain a positive and cheerful outlook on the current situation, 20.3% (16) said sickle cell disease people seldom maintain a positive and cheerful outlook on the current situation, 30.4% (24) agreed that they sometimes maintain a positive and cheerful outlook on the current situation, 27.8% (22) agreed that they often maintain a positive and cheerful outlook on the current situation while 16.5% (13) agreed that maintaining a positive and cheerful outlook on the current situation was done very often by people with sickle cell disease. 32.9% (26) of the respondents agreed that people with sickle cell disease never accept one's best efforts and that there is nothing further to be done, 22.8% (18) agreed that they seldom accept one's best efforts and that there is nothing further to be done, 19% (15) agreed that they sometimes accept one's best efforts and that there is nothing further to be done, 16.5% (13) agreed that people with sickle cell disease often accept one's best efforts and that there is nothing further to be done while 8.9% (7) agreed that sickle cell disease people accept one's best efforts and that there is nothing further to be done very often. 25.3% (20) of the respondents agreed that sickle cell disease people let others know what is of concern and enlist support by organize on activity, 24.1% (19) agree that they seldom let others know what is of concern and enlist support by organize on activity, 30.4% (24) agreed that people with sickle cell disease sometimes let others know what is of concern and enlist support by organize on activity, 11.4% (9) of the respondents agreed that people with sickle cell disease often let others know what is of concern and enlist support by organize on activity while 8.9% (7) agreed that they let others know what is of concern and enlist support by organize on activity very often. 12.7% (10) of the target population agreed that people with sickle cell disease never

use a professional adviser such as counselor, 12.7% (10) agreed that people with sickle cell disease seldom use a professional adviser such as counselor, 17.7% (14) said they sometimes use a professional adviser such as counselor, 31.6% (25) said sickle cell disease people often use a professional adviser such as counselor while 25.3% (20) agreed that people with sickle cell disease use a professional adviser such as counselor very often. A total of 17.72% agreed that the people with sickle cell disease never adopted in the above coping strategies, 18.63% agreed that the above coping strategies were seldom adopted by people with sickle cell disease, 29.11% agreed that those above coping strategies were sometimes adopted by the people with sickle cell disease, 22.66% agreed that the above coping strategies were often adopted while 11.91% of the respondents agreed that the strategies were adopted very often by people with sickle cell disease.

## TESTING OF HYPOTHESIS

### Hypothesis 1

There is no significant difference between psychosocial impact and coping strategies among respondents.

**Table 6**

	t-test for Equality of Means					Psychosocial Impact	Coping strategies
	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	Mean	Std. Deviation
Equal variances assumed	-.307	156	.759	-.354	1.155	18.78	8.086
Equal variances not assumed	-.307	147.52	.759	-.354	1.155	19.14	6.332

Above table 6 shows the t-test for equality of mean between psychosocial impact and coping strategies among respondents. The P value shows 0.759 with level of significance of 0.05. since the P value of 0.759 is greater than 0.05, the state hypothesis 1 is hereby accepted i.e. there is no significant different between psychosocial impact and coping strategies among respondents.

### Hypothesis 2

There is no significant relationship between knowledge of causes and demographic characteristics of respondents.

**Table 7**

CONTROL VARIABLES		Gender	Age	Ethnic group	LGA	Current Living Status	Marital Status	Religion
KNOWLEDGE ABOUT THE CAUSE	Correlation	0.126	0.003	0.024	-0.055	-0.055	0.041	-0.151
	Significance (2-tailed)	0.27	0.976	0.855	0.83	0.627	0.721	0.184
	D.F	77	77	77	77	77	77	77

The multiple correlations show the following P values of 0.27, 0.976, 0.855, 0.83, 0.627, 0.721 and 0.184. Since P values are greater than 0.05, the stated hypothesis 2 is hereby accepted i.e. there is no significant relationship between knowledge of cases and demographic characteristics of respondents.

### Hypothesis 3

There is no significant relationship between knowledge of causes and coping strategies among respondents

**Table 8**

		Coping strategies	Knowledge about causes
ADAPTING PRODUCTIVE COPING STYLES	Pearson Correlation	1	0.103
	Sig. (2-tailed)		0.365
	N	79	79
KNOWLEDGE ABOUT THE CAUSES	Pearson Correlation	0.103	1
	Sig. (2-tailed)	0.365	
	N	79	79

The correlations coefficient P values of values 0.36 (2) were Igbo. In respect to the local government area each respondents was from, 16.5% (13) of the target population were from Ogbomoso South Local Government (OSLG), 60.8% (48) 5, since the P value is greater than 0.05, the stated hypothesis 3 is hereby accepted i.e. there is no significant relationship between knowledge of causes and coping strategies among respondents.

## DISCUSSION OF FINDINGS

The discussion of findings is based on the data collected through questionnaires from the respondents i.e. people living with sickle cell disease in Ogbomoso North Local Governments, Oyo State.

Table 2 showing the respondents distribution on what the term sickle cell disease imply, from the table, 11.4% (9) of the respondents agreed that sickle cell disease is a hereditary blood disorder characterized by abnormality in the oxygen-carrying haemoglobin molecules in red blood cells, 7.6% (6) said that sickle cell disease is a condition which occurs when a person inherits two abnormal copies of the haemoglobin gene, 1.3% (1) agree that sickle cell disease is a condition that leads to a propensity for the cell to assume an abnormal rigid sickle cell like shape, 77.2% (61) agreed to all the terms while 2.5% (2) gave no response, this indicates that majority of the respondents had full knowledge about the concept of sickle cell disease. This might probably be due to the fact that the respondents were victims of the condition.

On the mode of getting sickle cell disease, 96.2% (76) of the target population agreed that the mode of getting sickle cell disease is when a person inherits two abnormal copies of the haemoglobin gene while 3.8% (3) gave no response. 94.9% (75) of the respondents agreed that sickle cell disease affects all age groups and both sexes while 5.1% (4) gave no response. 92.4% (73) agreed that couple with sickle cell trait is at risk of having sickle child/children while 7.6% (6) gave no response, 94.9% (75) of the target population agree that a person with a single abnormal copy does not experience symptoms and is said to have sickle cell trait while 5.1% (4) gave no response to the question.

From the finding above, it imply that majority of the respondents had full knowledge about the concept of sickle cell disease.

Above description is according to National Heart, Lung and Blood Institute (NHLBI, 2013). Sickle cell anaemia is a blood disorder that causes abnormally shaped red blood cells. Normal blood cells are disk-shaped with an indentation in the center, and they move smoothly through the blood vessels. (CRSCD, 2014) stated that sickle cell disease is the most common inherited blood disorder which is caused by a mutation in the heamoglobin-Beta gene found on chromosome II. Hemoglobin transports oxygen from the lungs to other parts of the body. Red blood cells with normal haemoglobin (hemoglobin A) are smooth and round and glide through blood vessels.

The analysis above gave answer to the research question 1 which stated that *“what does the term sickle cell disease imply?”*

Table 3 showings the distribution of respondents on the psychosocial impact of sickle cell disease among people living with sickle cell disease, which was widely distributed, from the table, 29.1% (23) of the respondents agreed that Anxious mood is not present, 25.3% (20) agreed that Anxious mood is mild, 30.4% (24) said it is moderate, 11.4% (9) agreed that it is severe while 3.8% (3) agreed that Anxious mood is very severe among people living with sickle cell disease. This indicates that these set if people have taken their conditions as one of the challenges of life, hence doesn't have much impact in their lives.

As for the level of tension as a psychosocial impact of sickle cell disease among the sickle cell disease people, % (20) agreed that it is not present, 30.4% (24) agreed that it is mild, 29.1% (23) agreed that it is moderate, 8.9% (7) agreed that it is severe while 6.3% (5) of the

respondents agreed that it is very severe, this indicate that majority of the respondents carrying the highest represented group claimed that their level of tension on sickle cell disease was mild which implied that the victims were getting used to the condition.

In the same vein, as for fear, 19% (15) of the respondents agreed that it is not present, 29.1% (23) agreed that it is mild, 32.9% (26) agreed that it is moderate, 11.4% (9) agreed that it is severe while 7.6% (6) of the respondents agreed that it is very severe among people living with sickle cell disease, indicating that majority of the respondents claimed that their level of fear concerning their condition as sickler was moderate while those that claimed that their level of fear were the least represented group, which implied that, most of the victims did not allow the condition to way them down. On the issue of whether they normally experience insomnia, from the same table, 34.2% (27) of the target population said that Insomnia is not present, 24.1% (19) agreed that Insomnia is mild, 29.1% (23) said it is moderate, 8.9% (7) said it is severe among sickle cell disease people this implied that higher percentage of the respondents carrying 34.2% (27) of the respondents carrying agreed that insomnia was not present.

As regard depressed mood, 30.4% (24) of the respondents agreed that Depressed mood is not present, 35.4% (28) agreed that Depressed mood is mild, 17.7% (14) said it is moderate, 11.4% (9) agreed that it is severe while 5.1% (4) agreed that Depressed mood is very severe among people living with sickle cell disease indicating that the respondents that supported that depressed mood was mild carried the highest represented group with 34.4%, this implies that this condition doesn't have much impact in their daily activities. The above findings negate the view of Annie, Egunjobi and Akinyanju (2011) who opined that mood is an important consequence of sickle cell disease i.e. people with sickle cell disease commonly have low self-esteem and feelings of hopeless as a result of frequent pain, hospitalizations and loss of schooling and employment. These accounts could indicate depressive symptoms, feeling of anxiety and self-hate were common. Even in Nigeria most of these people with sickle cell disease were worried and had depressive thought about their condition. Likewise the view of Morinka (2008) who stated that in assessing the seriousness of this disease (SCD) no one should underestimate its emotional and social impact. The patients endures not only the pain itself, but also the emotional strain from unpredictable bouts of pain, fear of death, and host time and social isolation at school and work.

As for intellectual as a psychosocial impact of sickle cell disease among people living with sickle cell disease, 24.1% (19) of the respondents agreed that it is not present, 22.8% (18) agreed that it is mild, 45.6% (36) agreed that it is moderate while 7.6% (6) said it is very severe, which indicate that these claimed that their intellectual was moderate carried the highest represented group with 45.6% (36). The implication of this is that their educational status will widen their knowledge of the treatment coping strategies aiming at managing their condition well without much stress. This finding is contrary to the opinion of Adegoke and Kuteyi (2010) that frequent school absenteeism as a result of recurrent crisis and suboptimal health is another major problem of sickle cell disease children.

As for somatic (sensory) 31.6% (25) of the respondents agreed that it is not present, 19% (15) agreed that it is mild, 32.9% (28) agreed that it is moderate, 5.1% (4) agreed that it is severe while 11.4% (9) of the respondents agreed that it is very severe among people living with sickle cell disease. 51.9% (41) of the target population said that cardiovascular symptoms is not present, 26.6% (21) agreed that it is mild, 15.2% (12) said it is moderate, 5.1% (4) said it is severe while 1.3% (1) agreed that cardiovascular symptoms is very difficult among sickle cell disease people. As for Respiratory symptoms as a psychosocial impact among people with

sickle cell disease, 49.4% (39) of the respondents agreed that it is not present, 34.2% (27) agreed that it is mild, 11.2% (9) agreed that it is moderate, 2.5% (2) agreed that it is severe while 2.5% (2) said it is very severe. 53.2% (42) of the respondents agreed that Gastrointestinal symptoms is not present, 24.1% (19) agreed that it is mild, 19% (15) said it is moderate, 2.5% (2) agreed that it is severe while 1.3% (1) agreed that it is very severe among people living with sickle cell disease. As for Genitourinary symptoms as a psychosocial impact among sickle cell disease people, 62% (49) agreed that it is not present, 21.5% (17) agreed that it is mild, 13.9% (11) agreed that it is moderate while 2.5% (2) of the respondents agreed that it is very severe. As for Autonomic symptoms, 44.3% (35) of the respondents agreed that it is not present, 39.2% (31) agreed that it is mild, 13.9% (11) agreed that it is moderate while 2.5% (2) agreed that it is severe among people living with sickle cell disease. 35.4% (28) of the target population said that Behaviour at Interview is mild, 25.3% (20) said it is moderate, 7.6% (6) said it is severe while 3.8% (3) agreed that it is very difficult among sickle cell disease people. As for Financial incapacitation as a psychosocial impact among people with sickle cell disease, 38% (30) of the respondents agreed that it is not present, 19% (15) agreed that it is mild, 31.6% (25) agreed that it is moderate, 6.3% (5) agreed that it is severe while 5.1% (4) said it is very severe. 70.9% (56) of the respondents agreed that Family disharmony as a psychosocial impact on sickle cell disease people is not present, 12.7% (10) agreed that it is mild, 13.9% (11) agreed that it is moderate while 2.5% (2) agreed it is severe in people with sickle cell disease. Lastly, 50.6% (40) of the target population agreed that Peer Group Isolation is not present in people with sickle cell disease, 21.5% (17) agreed that it is mild, 19% (15) agreed that it is severe while 6.3% (5) agreed that Peer group isolation as a psychosocial impact is very severe in people with sickle cell disease. A total of 39.2% agreed that all the listed psychosocial impact is not present in people with sickle cell disease, 25.62% agreed that the above psychosocial impact is mild in people with sickle cell disease, 24.18% of the respondents agreed that above psychosocial impacts is moderate in sickle cell disease people, 5.81% agreed that the impact on people with sickle cell disease is severe while 4.76% of the target population agreed that above psychosocial impact on people with sickle cell disease is very severe. This therefore give answer to research question 3 which stated that ***“what are the psychosocial impact of sickle cell disease among people living with sickle cell disease?”***

The psychosocial effects among people living with sickle cell disease were shown in table 4, 30.4% (24) of the respondents agreed that Depressed mood is not present, 35.4% (28) agreed that Depressed mood is mild, 17.7% (14) said it is moderate, 11.4% (9) agreed that it is severe while 5.1% (4) agreed that Depressed mood is very severe among people living with sickle cell disease. 51.9% (41) of the target population said that cardiovascular symptoms is not present, 26.6% (21) agreed that it is mild, 15.2% (12) said it is moderate, 5.1% (4) said it is severe while 1.3% (1) agreed that cardiovascular symptoms is very difficult among sickle cell disease people. As for Respiratory symptoms as a psychosocial impact among people with sickle cell disease, 49.4% (39) of the respondents agreed that it is not present, 34.2% (27) agreed that it is mild, 11.2% (9) agreed that it is moderate, 2.5% (2) agreed that it is severe while 2.5% (2) said it is very severe. 53.2% (42) of the respondents agreed that Gastrointestinal symptoms is not present, 24.1% (19) agreed that it is mild, 19% (15) said it is moderate, 2.5% (2) agreed that it is severe while 1.3% (1) agreed that it is very severe among people living with sickle cell disease. This implies that this group of people i.e. people living with sickle cell disease received better treatment from both the health care providers and the family as a result of their wider knowledge about SCD. Hence, there is less problem of depressed mood and other cases of cardiovascular, respiratory and gastrointestinal symptoms or complications observed in them. This finding is contrary to the view of Global Burden of Disease study, 2013 and Yawn,

Buchanan, Ballas, Hassell and James (2014) who opined that acute chest syndrome is defined by at least two of the following signs or symptoms: Chest pain, Fever, Pulmonary infiltrate or Focal abnormality, Respiratory symptoms or Hypoxemia. It is the second-most common complication and it accounts for about 25% of deaths in patients with sickle cell disease, majority of cases present with vaso-occlusive crises then they develop acute chest syndrome. Nevertheless, 80% of patients have vaso-occlusive crises during acute chest syndrome. Also amongst the chronic cardiopulmonary complications of sickle cell disease, pulmonary hypertension has emerged as the major threat to the well-being and longevity of patients with sickle cell disease.

As for Financial incapacitation as a psychosocial impact among people with sickle cell disease, 38% (30) of the respondents agreed that it is not present, 19% (15) agreed that it is mild, 31.6% (25) agreed that it is moderate, 6.3% (5) agreed that it is severe while 5.1% (4) said it is very severe. This negates the opinion of Adegoke and Kuteyi (2012) who claimed that about 70% of the caregivers lost income or financial benefits due to time spent caring for their children. In Nigeria, the predominant form of health care financing is out-of-pocket. As observed previously above, job loss, under employment and/or unemployment arising from time spent caring for a child with sickle cell disease, will significantly contribute to the financial burden experienced by caregivers and their family.

70.9% (56) of the respondents agreed that Family disharmony as a psychosocial impact on sickle cell disease people is not present, 12.7% (10) agreed that it is mild, 13.9% (11) agreed that it is moderate while 2.5% (2) agreed it is severe in people with sickle cell disease, this negates the opinion of Tunde Ayinmode (2008) who stated that when an individual behaves in a way to change an impact he may simultaneously create another e.g. the taking on of extra work by mother of a sickle cell disease child to reduce the financial burden of sickle cell disease, may mean an increased risk of physical, social and emotional neglect of her family with consequent marital disharmony.

Lastly, 50.6% (40) of the target population agreed that Peer Group Isolation is not present in people with sickle cell disease, 21.5% (17) agreed that it is mild, 19% (15) agreed that it is severe while 6.3% (5) agreed that Peer group isolation as a psychosocial impact is very severe in people with sickle cell disease. This finding is in disagreement with the opinion of Anie, Egunjobi and Akinyanju (2011) that anecdotal evidence suggest teasing and bullying are common complaints among school going children with sickle cell disease. Other major psychosocial problems experienced by young people with sickle cell disease during their school going years have also been described important issues include fear of early death, fears of talking to friends and teachers about the condition, embarrassment about bedwetting and reluctant to take part in school trips because of this teasing by colleagues due to jaundice and associated discolouration of their eyes, and anger should ill-informed staff consider the child as lazy and wanting to keep away from school activities. Anxieties that young people with sickle cell disease experience at school may result in the development of a negative image of themselves, teachers and school staff. A total of 49.2% agreed that all the listed psychosocial effects is not present in people with sickle cell disease, 24.79% agreed that the above psychosocial effects is mild in people with sickle cell disease, 18.2% of the respondents agreed that above psychosocial effects is moderate in sickle cell disease people, 4.3% agreed that the impact on people with sickle cell disease is severe while 3.44% of the target population agreed that above psychosocial effects on people with sickle cell disease is very severe. From the findings analyzed above, the researcher can infer the both the family and the peer group had



group understanding and awareness about sickle cell disease, hence, they showed great concern and positive attitude towards people living with sickle cell disease. This therefore provides answer to research question 4 which stated that ***“what are the psychosocial effects of sickle cell disease on the people living with sickle cell disease”?***

The table 5 above shows the specific coping strategies adopted by people living with sickle cell disease. 35.4% (28) agreed that sharing the problem with others and enlisting support in its management was never a coping strategy adopted by people living with sickle cell disease, 15.2% (12) seldom sharing the problem with others and enlisting support in its management, 31.6% (25) agreed that people with sickle cell disease sometimes share the problem with others and enlisting support in its management, 7.6% (6) agreed that they often sharing the problem with others and enlisting support in its management while 10.1% (8) agreed that they sharing the problem with others and enlisting support in its management very often. 13.9% (11) of the respondents said people with sickle cell disease never reflect on the problem, plan solutions and tackle the problem systematically, 17.7% (14) said they seldom reflect on the problem, plan solutions and tackle the problem systematically, 30.4% (24) of the respondents said people with sickle cell disease sometimes reflect on the problem, plan solutions and tackle the problem systematically, 29.1% (23) said sickle cell disease people often reflect on the problem, plan solutions and tackle the problem systematically while reflecting on the problem, plan solutions and tackle the problem systematically was adopted very often by people with sickle cell disease as agreed by 8.9% (7) of the respondents. 17.7% (14) said sickle cell disease people never engage in playing sport and keeping fit, 39.2% (16) said sickle cell disease seldom play sport and keeping fit, 16.5% (13) agreed that they often play sport and keeping fit while 6.3% (5) agreed that playing sport and keeping fit was adopted very often by sickle cell disease people. 6.3% (5) agreed that engaging in general leisure activities not sport either alone or with others was never a copying strategy adopted by people living with sickle cell disease, 22.8% (18) agreed that they seldom engage in general leisure activities not sport either alone or with others, 35.4% (28) agreed that people with sickle cell disease sometimes engage in general leisure activities not sport either alone or with others, 32.9% (26) agreed that they often engage in general leisure activities not sport either alone or with others while 2.5% (2) agreed that they engage in general leisure activities not sport either alone or with others very often. 15.2% (12) agreed that engaging in a particular intimate relationship was never a coping strategy adopted by people living with sickle cell disease, 12.7% (10) agreed that they seldom engage in a particular intimate relationship, 36.7% (29) agreed that people with sickle cell disease sometimes engage in a particular intimate relationship, 22.8% (18) agreed that they often engage in a particular intimate relationship while 12.7% (10) agreed that they engage in a particular intimate relationship. 12.7% (10) of the respondents said people with sickle cell disease never have commitment, ambition and industry, 20.3% (16) of the respondents said people with sickle cell disease sometimes have commitment, ambition and industry, 17.7% (14) said they seldom have commitment, ambition and industry, 20.3% (16) said people with sickle cell disease sometimes have commitment, ambition and industry, 30.4% (24) said they often have commitment, ambition and industry while having commitment, ambition and industry was adopted very often by people with sickle cell disease as agreed by 8.9% (7) of the respondents. 5.1% (4) said sickle cell disease people never maintain a positive and cheerful outlook on the current situation, 20.3% (16) said sickle cell disease people seldom maintain a positive and cheerful outlook on the current situation, 30.4% (24) agreed that they sometimes maintain a positive and cheerful outlook on the current situation, 27.8% (22) agreed that they often maintain a positive and cheerful outlook on the current situation while 16.5% (13) agreed that maintaining a positive and cheerful outlook on the current situation was done very often

by people with sickle cell disease. 32.9% (26) of the respondents agreed that people with sickle cell disease never accept one's best efforts and that there is nothing further to be done, 22.8% (18) agreed that they seldom accept one's best efforts and that there is nothing further to be done, 19% (15) agreed that they sometimes accept one's best efforts and that there is nothing further to be done, 16.5% (13) agreed that people with sickle cell disease often accept one's best efforts and that there is nothing further to be done while 8.9% (7) agreed that sickle cell disease people accept one's best efforts and that there is nothing further to be done very often. 25.3% (20) of the respondents agreed that sickle cell disease people let others know what is of concern and enlist support by organize on activity, 24.1% (19) agree that they seldom let others know what is of concern and enlist support by organize on activity, 30.4% (24) agreed that people with sickle cell disease sometimes let others know what is of concern and enlist support by organize on activity, 11.4% (9) of the respondents agreed that people with sickle cell disease often let others know what is of concern and enlist support by organize on activity while 8.9% (7) agreed that they let others know what is of concern and enlist support by organize on activity very often. 12.7% (10) of the target population agreed that people with sickle cell disease never use a professional adviser such as counselor, 12.7% (10) agreed that people with sickle cell disease seldom use a professional adviser such as counselor, 17.7% (14) said they sometimes use a professional adviser such as counselor, 31.6% (25) said sickle cell disease people often use a professional adviser such as counselor while 25.3% (20) agreed that people with sickle cell disease use a professional adviser such as counselor very often. A total of 17.72% agreed that the people with sickle cell disease never adopted in the above coping strategies, 18.63% agreed that the above coping strategies were seldom adopted by people with sickle cell disease, 29.11% agreed that those above coping strategies were sometimes adopted by the people with sickle cell disease, 22.66% agreed that the above coping strategies were often adopted while 11.91% of the respondents agreed that the strategies were adopted very often by people with sickle cell disease. This therefore provided answer to research question 5 which stated that *"what are the specific coping strategies being adopted by people living with sickle cell disease?"*

## SUMMARY

The study investigated the perceived psychosocial impact and coping strategies among people living with sickle cell disease in Ogbomoso North Local Government, Oyo State, Nigeria. Sickle Cell Disorder has been defined as an inherited birth disorder from parents to the child, it arises when a baby inherits the gene for sickle haemoglobin (HBs) or a hereditary blood disorder, characterized by an abnormality in the oxygen-carry haemoglobin molecule in red blood cells that leads to a propensity for the cells to assume an abnormal, rigid, sickle-like shape under certain circumstances. The study explores the psychosocial impact of sickle cell disease (SCD) and the coping strategies of people living with sickle cell disease (SCD) in Ogbomoso North Local Government.

## CONCLUSION

It was discovered that majority of the respondents know and identified what sickle cell disease mean and that the mode of getting sickle cell disease is when a person inherits two abnormal copies of the haemoglobin gene.

That sickle cell disease affects all age groups and both sexes and that a person with a single abnormal copy does not experience symptoms and is said to have sickle cell trait.

This study has demonstrated that the psychosocial impact of SCD has high negative impact on persons living with sickle cell disease, their guardian and parents with stress of lack of fiancé to support their wards or children living with sickle cell diseases. It has provided an analysis of the perception and predisposing factors leading to the incidence of sickle cell disease among people. The lack of awareness, high level of illiteracy in Nigeria has led to the rising increase of SCD. This has made the incidence of sickle cell disease in Nigeria high.

In view of the result of this study, the researcher can infer that sickle cell disease (SCD) is an important but largely neglected risk to child survival in most African countries of which Nigeria is inclusive hence greater attention to reducing mortality from sickle cell disease could help some Africa Governments to achieve their targets with regard to Millennium Development Goal (MDG) number 4 i.e. to reduce their under 5 mortality rates by two third (2/3).

In the aspect of the psychosocial impacts of sickle cell disease on the people living with sickle cell disease which is the main focus of the study, tension, fears, insomnia, intellectual, depressed mood, somatic (muscular), somatic (sensory), cardiovascular symptoms, respiratory symptoms, gastrointestinal symptoms, genitourinary symptoms, autonomic symptoms, behavior at interview, financial incapacitation, family disharmony and peer group isolation are psychosocial impacts among people living with sickle cell disease.

### **Implication for Nursing Practice**

According to the findings of this research result of the study revealed that the global burden of sickle cell disease is increasing and this psychosocial problems occurring concurrently both in sickle cell disease patients and their caregivers (parents) is a phenomenon that can have negative impacts both on the victims and the family as a whole. Hence, this study suggests that patients should be seen by nurses and other health care provider in the context of their families holistically. Whenever a sickle cell disease child or mother is identified to have psychosocial problems the minimum of psychosocial assessment should include both sickle cell disease patients and their parents need to be assessed too. Therefore nurses and policy makers should provide the necessary psychological care and support to these individuals in order to have a better success of the treatment/management of the affected people.

### **RECOMMENDATIONS**

Based on the findings from the study, the following recommendations are therefore made:

1. Government of various countries should strengthen the existing national health insurance as well as subsidizing the cost of sickle cell disease (SCD) care to alleviate the huge financial burden on the family.
2. Regular psychosocial support should be available to alleviate caregivers and or family members' burden.
3. Social organizations i.e. National Sickle Cell Association and Sickle Cell Club should be encouraged so that sickle cell disease victims and their caregivers can share their feelings and counsel among one another.

4. Promotion of neonatal screening genetic counseling and comprehensive public health education aiming at increasing community awareness on the burden and prevention of the disease.
5. Routine haemoglobin genotype determination for adolescents before entering into marital relationships to offer a programmatic approach in reducing the high prevalence of the sickle cell gene and the attendant problems.
6. Health Education on limitation of family size to reduce the risk of mothers from having additional sickle cell disease children.

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