COPING STRATEGIES OF MOTHERS OF SCHOOL AGED CHILDREN WITH SICKLE CELL DISEASE IN ENUGU METROPOLIS, ENUGU STATE, NIGERIA

BY

OBI, IFEYINWA NNEAMAKA (BChD)

REG. NO: 20144919378

A THESIS SUBMITTED TO THE POSTGRADUATE SCHOOL FEDERAL UNIVERSITY OF TECHNOLOGY, OWERRI

IN PARTIAL FULFILMENT OF THE REQUIREMENTS FOR THE AWARD OF MASTER OF PUBLIC HEALTH (MPH)

SEPTEMBER, 2021

COPING STRATEGIES OF MOTHERS OF SCHOOL AGED CHILDREN WITH SICKLE CELL DISEASE IN ENUGU METROPOLIS, ENUGU STATE, NIGERIA

BY

OBI, IFEYINWA NNEAMAKA (BChD)

REG. NO: 20144919378

A THESIS SUBMITTED TO THE POSTGRADUATE SCHOOL FEDERAL UNIVERSITY OF TECHNOLOGY, OWERRI

IN PARTIAL FULFILMENT OF THE REQUIREMENTS FOR THE AWARD OF THE DEGREE (MASTER OF PUBLIC HEALTH), MPH IN HEALTH PROMOTION

SEPTEMBER, 2021

CERTIFICATION

This is to certify that this work **"Coping strategies of mothers of school aged children with sickle cell disease in Enugu metropolis, Enugu state, Nigeria"** was carried out by **Obi, Ifeyinwa Nneamaka (Reg. 20144919378),** in partial fulfilment for the award of the Degree of Masters of Public Health (MPH) in Health Promotion Technology in the Department of Public Health of the Federal University of technology, Owerri.

.....
Dr. (Mrs.) Blessed Nworuh
(Principle Supervisor)

1/2/2022
Date

.....
Prof. (Mrs.) E.A. Nwoke
(Co-Supervisor)

.....
Date

.....
Dr. U.M. Chukwuocha
HOD (Public health)

01/02/22
Date

.....
Prof. P.U. Agbasi
Dean (School of Health Technology)

1/2/22
Date

.....
Prof. C.C Eze
Dean (PG school)

.....
Date

.....
Prof. D.F.E. Nwagbo
External Examiner

24/9/22
Date

DEDICATION

This Project is dedicated to all the hard working mothers in Nigeria relentlessly taking care of their young sick children.

ACKNOWLEDGEMENTS

Foremost, I want to thank Almighty God whose infinite mercies sustained me through this work and academic sessions.

Special thanks to the Dean of School of Health Technology Prof P.U. Agbasi, and H.O.D Prof. (Mrs.) E.A. Nwoke for their support and assistance. I also want to appreciate all the lecturers in the Department of Public Health especially Prof. A.C. Okwuoma, Prof. N.A Amadi, Prof I.N.S Dozie, Rev. Sr (Prof.) E.T. Oparaocha, Dr. (Mrs.) S.N.O Ibe , Dr. C.C.A Okereke, Dr C.R. Nwufo, Dr. (Mrs.) Amadi, Mr G.N Iwuoha in the various roles they played to ensure that this work is a success. My profound gratitude goes to my supervisors, Dr. (Mrs.) Blessed Nworuh and Prof. (Mrs) E.A. Nwoke for their guidance and encouragement during the course of this work.

I will like to acknowledge everyone whose input contributed to the success of this thesis, especially my classmates, Princewill Njoku, Pascal Nya, Chinaemenma Garba, Jane Okpi and Jessica Offiah.

Finally, my special appreciation goes to my lovely husband Mr Uchenna G. Obi and my adorable children, Kosisochukwu, Zara and Febenna for their undying love, support and encouragement.

TABLE OF CONTENTS

Chapter III: Materials and Method

LIST OF TABLES

APPENDICES

Definition of Terms

ALLELE: Each of two or more alternative forms of a gene that arise by mutation and are found at the same place on a chromosome.

COPING STRATEGIES: this is the process the mothers of school age children with sickle cell manage the stress confronting them while taking care of their children.

HbSC: Heamoglobin SC disease is the second most common type of sickle cell disease. It occurs when an individual inherit the Hb C gene from one parent and Hb S gene from the other.

HbSS: Heamoglobin SS is the most common type of sickle cell disease. It occurs when an individual inherit copies of the hemoglobin S gene from both parents.

HEAMOGLOBIN: Hemoglobin is a protein in red blood cell that carries oxygen throughout the body.

HETEROZYGOTE: An individual having two identical alleles of a particular gene and so breeding true for the corresponding characteristics.

HOMOZYGOTE: an individual having two different alleles of a particular gene or genes, and so giving rise to varying off spring.

IMPEDIMENTS: These are challenges mothers of school aged children with SCD encounter.

SICKLE CELL DISEASE: Sickle cell disease is a genetic blood disorder cause by the presence of an abnormal form of hemoglobin.

STRESS: It's a psychological or physical difficulties encountered by mothers of school aged children suffering SCD in dealing with their children's condition.

STRESSORS: These are factors that cause stress to mothers of school aged children suffering SCD.

ABSTRACT

The study on coping strategies of mothers of school aged children with sickle cell disease (SCD) in Enugu metropolis, Enugu state, Nigeria was carried out between June and August 2017. The overall objective was to determine the coping strategies of mothers of school age children with SCD accessing treatment in health facilities in Enugu metropolis. To achieve the overall objectives, four specific objectives were set. This study was designed as a cross sectional study and a sample size of 292 mothers were selected using the systematic sampling method from a total population of 460 mothers whose children were accessing treatment for SCD from both UNTH and ESUTH. One hundred and fifty-four (154) were chosen from UNTH while one hundred and thirty-eight (138) were from ESUTH. A structured questionnaire (0.88) was used as instrument for data collection. Data analysis was done using chi-square test and significance was tested at $P<0.05$. The marital status of mothers showed that, 200 (68.5%) mothers were married and 92(31.5%) were single. Regarding the number of school age children suffering SCD per mother, the result showed that, 248(84.9%) mothers had one child suffering SCD and 44(15.1%) mothers had more than one child suffering sickle cell disease. The result on stressors confronting the mothers shows six factors which were; hospital factors, child factors, financial factors, psychological factors, disease factors and family factors. The association between these factors and marital status of these mothers were significant ($P<0.05$), aside from disease factors which had no significant association with the marital status of the mothers. ($X^2=0.000$, $P=1.000$, $df=2$). Hospital factors were coped through confronting the impediments 180(61.6%), financial factors were coped through complaints 202(69.1%), child factors were coped through confronting the stressors, psychological factors were coped through complaints 140(47.9%), disease factors were coped through complaints 292(100.0%) and family factors were mainly coped through confronting the stressors. There were significant associations between coping mechanisms adopted by mothers and mothers marital status ($P<0.05$), aside from coping mechanisms on disease factors which had no significant association with marital status of the mothers. This study has shown that both married and single mothers of children with SCD experience significant stress which they adopt various ways of coping with. It is important for policy makers to provide necessary psychological care and support for these women in other to alleviate their stress.

Key words: Sickle cell disease, School aged, Coping strategies,

Stress, Stressors, Confronting and Alleviate.

CHAPTER I

Introduction

1.1 Background Information

Managing a life-long chronic illness such as sickle cell disease (SCD) is burdensome on those affected and has been associated with psychological complications across the life span of sufferers. (Anie, 2005). Of equal concern should be the burden of disease on the mothers within the family. In the case of a disease that affects children from birth, it is the mother who bears most of the burden and is therefore subject to the most stress.

Stress, if not coped with, may be detrimental to health and manifest in problems such as coronary heart disease. While the results of stress have been amply documented in research on the male population, less is known about what happens when women experience stress (Schenck-Gustafsson & Orth-Gomer, 2000). Studies have found that working class women, who often lack strong social support systems, are three times more likely to experience coronary heart disease than their counterparts in white collar jobs (Prihartono, Fitriyani & Riyadina, 2018).

According to McBride and Black (1984), mothers appear to be more sensitive to troubled children, because it is the mothers who gave birth to the children. They are more likely to feel responsible for a diseased condition. Breslay (1983) established that, except in rare instances, it is the mother who will provide the extraordinary care required by a developmentally disabled child. Studies have shown that psychological distress among mothers of children with SCD may

influence the prognosis of the child (Diggs and Flower, 1971; Fleming *et al.*, 1979; Aniowu *et al.*, 1981). A particularly stressful aspect of SCD management is the unpredictability and episodic nature of the illness and its attacks on children. These continued attacks result in shopping around for a 'cure', placing mothers in the hands of often unscrupulous spiritual, herbal and even orthodox healers. There is also fear and anxiety related to the future of subsequent pregnancies (Rance & Skirton, 2019).

Sickle cell disease (SCD) is one of the commonest but preventable inherited diseases. It is a disease of the red blood cells and is a lifelong ailment which has been with man since the existence of man. Sickle cell disease affects all races of the world; it affects the people of tropical Africa, Mediterranean Sea, Middle East and South India. Sickle cell disease was first discovered in the African American populations in 1910 (Durham 1991), it has contributed significantly to the high childhood mortality rate.

Nigeria has an estimated population of 150 million with annual growth rate of 3.2% (Afolayan and Jolayemi, 2011). The current figure of individuals in Nigeria with this disease is not known since the majority born in rural community do not survive childhood and for lack of proper statistics. However, an estimate of about 2.3% of the Nigerian population suffers from sickle cell disease and about 25% of Nigerians are healthy carriers of the abnormal hemoglobin gene (Afolayan and Jolayemi, 2011). Also, Anie *et al* (2010), state that SCD is a global health problem with psychosocial implications and that

Nigeria has the largest population of people with SCD with about 150,000 births annually.

Although over 300,000 babies are born worldwide with SCD, mostly in low and middle income countries with the majority of these births in Africa (Anie *et al*, 2010). Apart from the attendant high morbidity, sickle cell disease also inflicts economic, psychological and physical strains on the patients' parents and their relations. Katibi (2008) stated that patients with sickle cell disease may have recurrent illness and be hospitalized due to various complications of the disease. The cost implication and mental agony of the parents in particular are of significant note. Katibi (2008) stated further that cost of daily maintenance of sickle cell patient is colossal in terms of drugs, nutrition, prevention of crisis, hospitalization and that the affected individuals or families suffer a burden of anxiety, frequent illness, excess mortality rates, ignorance and lack of appropriate health services and research. The following research questions guided the study:

i. What are the various stressors confronting mothers of school aged children with SCD accessing treatment in health facilities in Enugu metropolis?

ii. What are the coping strategies adopted by mothers of school aged children with SCD accessing treatment in health facilities in Enugu metropolis?

iii. What is the association between the various stressors confronting the mothers and marital status of mothers of school aged children with SCD accessing treatment in health facilities in Enugu metropolis?

iv. What is the association between coping strategies adopted by mothers

and marital status of the mothers of school aged children with SCD accessing treatment in health facilities in Enugu metropolis?

1.2 Problem Statement

An estimate of about 2.3% of the Nigerian population suffers from sickle cell disease and about 25% of Nigerians are healthy carriers of the abnormal hemoglobin gene (Afolayan and Jolayemi, 2011). Families who have children with sickle cell disease (SCD) endure numerous potentially stressful experiences and daily hassles related to the biological complications of SCD. These ordeals can cause difficulties with finances, work, transportation and changes to daily routines.

Mothers of children with SCD are at risk for excessive anxiety, depressed mood, guilt, social isolation and personal health problems (Afolayan and Jolayemi, 2011). Psychosocial issues for people with SCD and their families mainly result from the impact of pain and symptoms on their daily lives and society's attitudes to SCD and those affected (Noll *et al.*, 2008). Mothers of children with SCD may struggle to meet the demands of parenting. The nature of the child's disease, the need to manage symptoms, and the complexity of treatment all cause emotional strain (Hopia, Tomlinson, Paavilainen & Astedt-Kurki, 2004). Despite the high prevalence of sickle cell disease in Nigerian infants and recurrent morbidity as well as the high risk of early death, there is a paucity of data on the coping patterns, psychosocial impact and health-related quality of

life of sickle cell disease on mothers of children with SCD (World Health Organization, 2006). Against this backdrop, the present study explores the factors in patterns of coping of mothers of children with SCD in Enugu Metropolis, South Eastern Nigeria.

1.3 Objectives

The main objective of this study is to determine the coping strategies of mothers of school aged children with SCD taking treatment in tertiary health facilities in Enugu Metropolis.

In order to achieve the study overall objectives, the following are the specific objectives of this study:

1. To determine the various Stressors confronting mothers of school aged children with SCD accessing treatment in facilities in Enugu Metropolis.
2. To determine the coping strategies adopted by mothers of school aged children with SCD accessing treatment in health facilities in Enugu Metropolis.
3. To determine the association between the various stressors confronting the mothers and the marital status of the mothers of school aged children with SCD accessing treatment in health facilities in Enugu Metropolis.
4. To determine the association between coping strategies adopted by the mothers and the marital status of the mothers of school aged children with SCD accessing treatment in health facilities in Enugu Metropolis.

1.4 Hypotheses

H1: There is no significant association between the various stressors confronting mothers and the marital status of mothers of school aged children with SCD accessing treatment in health facilities in Enugu metropolis.

H2: There is no significant association between coping strategies adopted by mothers and marital status of mothers of school aged children with SCD accessing treatment in health facilities in Enugu metropolis.

1.5 Justification of Study

The findings of this study will reveal the stressors confronting mothers of children with SCD in Enugu metropolis and it shall also reveal ways mothers can use in coping with stress associated with child SCD. These stressors when taken into consideration will lead to planning appropriate programmes that will help improve coping patterns among mothers. It is anticipated that results of this research will bring to the fore critical issues related to stressors associated with child SCD and how these could be handled to help assuage psychological effects of stressors among mothers. Information from this study will also contribute to existing knowledge in this area and serve as literature for further similar study.

1.6 Scope of Study

The general objective of this study is to determine the factors in the coping patterns among mothers of school aged children with Sickle Cell Disease in

Enugu Metropolis. The population of the study was limited to mothers whose children were obtaining treatment at Enugu State University Teaching Hospital (ESUTH), and University of Nigeria Teaching Hospital (UNTH). These mothers include married mothers (women still living with their husbands) and single mothers (divorced ladies and ladies who never married but had children). The independent variables of the study are stressors associated with Child SCD and the dependent variables are the coping patterns implored by mother of children with SCD.

CHAPTER TWO

LITERATURE REVIEW

2.1 Conceptual Framework

This section reviews literatures on the incidence, prevalence, morbidity, and mortality of SCD among children in Africa; current practices and challenges related to screening, diagnosis, and treatment; and recommendations for practice, policy, and research to improve health outcomes of children with SCD in Africa based on the literature and on global guidelines.

2.1.1 Meaning of Sickle Cell Disease

Sickle cell disease (SCD) is one of the most common genetic diseases worldwide and its highest prevalence occurs in Middle East, Mediterranean regions, Southeast Asia, and sub-Saharan Africa especially Nigeria (Modell, & Darlison, 2008). SCD is a chronic haemolytic disorder that is marked by tendency of haemoglobin molecules within red cells to polymerise and deform the red cell into a sickle (or crescent) shape resulting in characteristic vaso-occlusive events and accelerated haemolysis (Aygun & Odame, 2012). It is inherited in an autosomal recessive fashion either in the homozygous state or double heterozygous state. When inherited in the homozygous state, it is termed sickle cell anaemia (SCA). Other known SCD genotypes include haemoglobin SC disease, sickle beta plus thalassemia, and sickle beta zero thalassemia (which has similar severity with sickle cell anaemia), haemoglobin SD Punjab disease, haemoglobin SO Arab disease, and others (Aygun & Odame, 2012).

In Nigeria, SCD forms a small part of the clinical practice of most general duty doctors, as there is gross absence of dedicated sickle cell centres. Thus, it may be difficult to keep abreast of current knowledge and practices in the treatment of SCD.

2.1.2 Epidemiology of Sickle Cell Disease

Of the 330,000 babies born with a major haemoglobinopathy worldwide, 275,000 have SCD, making it the major global haemoglobinopathy (Aygun & Odame, 2012; Modell & Darlison, 2008). SCD patients in the developed world account for only 10% of the world's SCD patient population (Aygun & Odame, 2012). In 2008, Aliyu *et al.* (2008) reported United Nations estimates that there are between 20 and 25 million people worldwide living with SCD, of which 12–15 million live in Africa. It is estimated that 75–85% of children born with SCD are born in Africa, where mortality rates for those under age 5 range from 50% to 80% (Aygun & Odame, 2012).

The highest prevalence of sickle-cell trait (SCT) in Africa occurs between the latitudes of 15° North and 20° south, where the prevalence ranges between 10% and 40% of the population (Agasa *et al.,* 2010). In 2010, Rawezula reported results of a study of records of over 2000 newborns at a hospital in Tanzania (Rwezaula, 2010). Findings indicated that 18.2% of the neonates had abnormal haemoglobin levels and that the incidence of abnormal haemoglobin levels differed based on the geographical regions of the newborns' parents. The

incidence of the SCT in Cameroon, the Democratic Republic of Congo, Gabon, Ghana, and Nigeria ranges from 20% to 30%, and in some parts of Uganda, the prevalence is 45% (Afolayan & Jolayemi, 2011; Anie, Egunjobi, & Akinyanju, 2010; Serjeant & Ndugwa, 2004; World Health Organization, 2006). Chakravorty and Williams (2015) suggested that there are few places where the carrier rate for SCD is greater than 25% because of the disadvantages conferred by homozygosity. Because many births occur outside of hospitals and many children die before diagnosis with SCD, there are limited statistical data on the incidence of SCD in Africa (Serjeant, 2010; Serjeant & Ndugwa, 2004). There is a need for additional research to gather accurate data about SCD prevalence in order to direct appropriate health care policies (Odunvbun, Okolo, &Rahimy, 2008). It has been suggested that one factor associated with the high incidence of SCD in tropical Africa is the protection against *Plasmodium* malaria associated with having the SCT (Aygun & Odame, 2012). The theory that the SCT offers some immunity against the malaria parasite was found to be strong in tropical Africa through a geo-statistical mapping study, but could not be explained in other parts of the world (Aygun & Odame, 2012). Migration from Africa and other regions with high rates of SCT and SCD has contributed to the global spread of SCD to areas such as North America and the Caribbean (Weatherall, 2011).

2.1.3 Mortality and Morbidity Rates of SCD

Mortality rates associated with SCD vary widely across the globe. Children born in high-resource countries with major haemoglobinopathies (including SCD) have higher chances of survival and lower mortality rates than those born in poor resourced countries (Aygun & Odame, 2012). The higher life expectancies for SCD patients in high resource countries may be due to earlier diagnosis, greater access to care, education of caregivers, and better disease management (Aygun & Odame, 2012; Modell & Darlison, 2008). The life expectancy for people with SCD in the United States (U.S.) is 42 and 48 years for men and women, respectively. Quinn, Rogers, McCavit, & Buchanan (2010) reported a 93.9% survival to adulthood of children diagnosed with SCD who were followed in Dallas, Texas. In Jamaica, life expectancy stands at 53 and 58.5 years for men and women, respectively (Wierenga, Hambleton, & Lewis, 2001).

The disease process in SCD causes complications in multiple body organs. Some of the most common morbidities associated with SCD include chronic pain and intermittent painful episodes, musculoskeletal problems, stroke, pulmonary hypertension, and septicaemia. These complications often co-exist, affecting the quality of life for patients, and if untreated, they may lead to death. Pain associated with vaso-occlusive crises is due to microvascular occlusions triggering the activation of nociceptive afferent nerve fibres (Stuart & Nagel, 2004). Children younger than 3 years are prone to painful swelling of the hands, known as hand-foot syndrome or dactylitis. Long bones and joints are

often areas of necrosis leading to pain. Micro vaso-occlusion in the mesenteric blood vessels also causes intense abdominal pain (Stuart & Nagel, 2004). In 2003, findings from a study of 236 SCD children (age 8 months–2 years) in Benin, and reported that that 77.5% experienced painful vaso-occlusive crises, with an average of 3.3 episodes per patient (Komba *et al.*, 2009).

Many children with SCD experience musculoskeletal complications due to a vascular necrosis, osteomyelitis, and septic arthritis. Balogun *et al*, (2010) published findings in 2004 from a study of 318 SCD patients in Nigeria. Study participants ranged from 1 to 45 years of age, and 46% below age 10. These authors noted that children below age 10 years were more likely to have multiple musculoskeletal problems, and reported that among the children younger than 10 years in this study, 95% had septic arthritis, 63.3% had osteomyelitis, and 7.2% had avascular necrosis of the femoral head. Among children between 11 and 20 years of age, 46.4% had avascular necrosis of the femoral head, 30.6% had osteomyelitis, and 5% had septic arthritis. Stroke due to vascular occlusion is one of the most serious complications of SCD (Kolapo & Vento, 2011). In high resource countries, it is estimated that the risk of developing a stroke among SCD patients is 250 times higher than for those without SCD (Makani, Williams, & Marsh, 2007). In 2009, Verduzco & Nathan (2009) reported findings from a study in the U.S. indicating that 24% of patients with SCD suffer a stroke by the age of 45 years. In 2001, Makani, Williams and Marsh estimated that the rate may even be higher in Africa due to the high prevalence of several risk factors including low hemoglobin,

leukocytosis, and the Bantu haplotype (Makani *et al.*, 2007). Children with SCD are more likely to suffer from pneumococcal disease than those who do not have SCD (Battersby *et al.*, 2010; Obaro, 2010). Battersby *et al* (2010), reported that septicaemia due to non-typhi Salmonella species and Klebsiella species was the most common cause of death in children below 5 years of age with SCD in Nigeria.

2.1.4 Prevention, Neonatal Screening and Treatment Strategies

Effective management of SCD revolves around genetic counselling, neonatal screening and early diagnosis; prophylaxis with immunizations; providing anti-malarial medications, antibiotics, and prompt management of complications. Bone marrow transplantation in a selected segment of patients is the only proven cure for SCD to date (Verduzco & Nathan, 2009), but this is an expensive treatment. Sergeant and Ndugwa (2004) note that this option is not feasible as a public health approach in low resource countries (Serjeant & Ndugwa, 2004).

2.1.5 Genetic Screening and Counselling

Several authors have suggested that prenatal screening and diagnosis could reduce the burden of haemoglobinopathies in poor resource countries (Kafando, Sawadogo, Cotton, Vertongen, & Gulbis, 2005; Weatherall, 2011). Modell and Darlison (2008) suggested that the use of genetic epidemiological data can help to assess SCD health care needs. In 2006, the World Health Organization

(WHO) identified a variety of medical genetic screening programs that are appropriate for low- and middle-income countries and that could help to reduce the incidence of SCD (World Health Organization, 2006). These programs include carrier identification using family pedigrees and screening tests, and postnatal screening for sickle cell disorders. The success of SCD prevention through heterozygote detection and premarital screening is influenced by the knowledge and attitudes of healthcare providers and community members about SCD and its treatment (Abioye-Kuteyi, Oyegbade, Bello, & Osakwe, 2009).

Abioye-Kuteyi *et al.* (2009), reported results of a survey of 320 government workers in Nigeria. Findings indicated that 69% had poor knowledge about SCD, although 95% had positive attitudes towards premarital screening. These researchers also reported that 86.7% of respondents and 74% of their partners had had sickle cell screening. Although 25% of the married and engaged respondents did not know their partner's sickle cell status, 33–66% indicated that they would continue the relationship with their partner if either or both had haemoglobinopathy (Abioye-Kuteyi *et al.*, 2009).

Prenatal genetic testing as a means of prevention and control of genetic diseases including SCD has been suggested as one of the effective ways of eradicating genetic haemoglobinopathies. However, Ahmed, Atkin, Hewison and Green (2006) noted that such testing may result in ethical and moral challenges because positive results may suggest termination of the pregnancy. Animasahun, Akitoye and Njokanma (2009) reported findings from a cross-

sectional survey of health workers at a teaching hospital in Nigeria. Although 91.3% had heard about SCD prenatal screening, only 75.3% knew that SCD could be prevented by prenatal screening. A total of 48.2% of these health workers were not aware that prenatal screening was available in Nigeria; and 42.1% would not allow preventive termination of pregnancy for positive screening results.

2.1.6 Screening

Tshilolo *et al* (2008) noted that in high resource countries where newborn screening has been introduced, patients are enrolled into comprehensive care programs resulting in better outcomes than in lower resource countries without comprehensive screening programs. Rahimy *et al,* suggested that the introduction of newborn screening in the developed world 20 years ago has cut down the mortality rate for SCD from 16% to >1% (Rahimy *et al.*, 2003). Early neonatal screening for SCD enables the implementation of a comprehensive care approach including prophylactic treatment, parental education, and initiation of a tracking and follow-up program for identified patients (Ohene-Frempong, Oduro, Tetteh, & Nkrumah, 2008).

In low resource countries, access to newborn screening for SCD or SCT is limited because of economic constraints. Odunvbun, Okolo, and Rahimy (2008) reported that despite the huge SCD burden in Africa and the advantages associated with newborn screening in the management of SCD, Benin and Ghana are the only two countries in Africa that have comprehensive newborn

screening programs. The program in Benin is however targeted at mothers with the SCT (Odunvbun*et al.*, 2008). Odunvbun, Okolo and Rahimy (2008) suggested that newborn screening would be widely accepted by parents in Nigeria. Better management protocols including early screening and comprehensive care may reduce mortality rate among children with SCD in Africa.

2.1.7 Prophylaxis Treatments of SCD

Obaro (2009) noted that the high rate of child mortality due to invasive bacteria in SCD children in Sub-Saharan Africa has not received global international attention, however use of childhood immunizations could reduce the incidence of this problem. Children with SCD need to receive routine immunizations based on the country-specific guidelines. Pneumococcal vaccinations and prophylaxis using penicillin has increased survival ratesamong children in the developed world (Makani *et al.*, 2007).

Aygun and Odame (2012) noted that improved immunization and better nutrition programs in many countries has improved survival among children with SCD. Development of vaccines against non-typhi Salmonellae may reduce childhood mortality in SCD (Obaro, 2010). Introduction of targeted interventions like penicillin prophylaxis and Pneumococcal vaccinations in the developed world has increased survival to 18 years of age to 94% in the U.S. and 99% in the United Kingdom (Cox *et al.*, 2011). There is disagreement among experts, however, as to whether penicillin prophylaxis and

pneumococcal vaccination are effective in Africa since some studies have shown that bacteremia in most African countries is not caused by S. pneumonia.

2.1.8 Malaria Prophylaxis

Makani *et al.* (2007) noted that although it was widely believed that malaria was a major cause of hospital admission and mortality among SCD patients in sub-Saharan Africa, there was a need to review the evidence about which drugs should be recommended for long-term prophylaxis among SCD patients. Aygun and Odame (2012) acknowledged that further research is needed to clarify the role of malaria as a cause of morbidity and mortality in SCD patients, but advised that the use of insecticide-treated bed nets along with anti-malarial prophylaxis during high risk seasons may be useful.

2.1.9 Traditional Herbal Remedies

Akinyanju, Otaigbe and Ibidapo (2005) reported that the use of traditional herbal remedies in the management of SCD is common practice in poor resourced countries such as Nigeria, where access to care is limited and the population is predominantly rural. In 2008, Okpuzor, Adebesin, Ogbunugafor, and Amadi (2008) reviewed medicinal plants with potential anti-sickling properties that have been used in low resource countries and described research that has been conducted to identify their beneficial effects.

There is a need for further studies on efficacy and effectiveness of these remedies (Akinyanju *et al.*, 2005). Such studies can be facilitated through partnerships between healers with knowledge of herbal remedies, and research organizations. One example of such a partnership is the development of NIPRISAN by collaboration between the National Institute for Pharmaceutical Research and Development (NIPRD) in Nigeria and members of the local communities with knowledge of herbal remedies. NIPRISAN is a phyto-medicine that was developed to manage SCD by NIPRD from local plants including *Piper Guineese* and *Eugenia Caryophllate* that have been used by the Yoruba people to treat SCD. In a 2001 report of a double blind, placebo controlled, randomized cross over clinical and laboratory study, NIPRISAN was found to be safe and effective in lessening the frequency of severely painful episodes (Wambebe *et al.*, 2001).

2.1.10 Treatment of Anaemia

Anaemia is a major cause of morbidity and mortality in SCD, and many patients die in hospital emergency rooms and wards before blood transfusions can be initiated. Ikefuna and Emodi (2007) reported results from a study of 71 children hospitalized for SCD in Nigeria. Findings indicated that 39.4%had severe anaemia, and that most cases were related to aplastic, acute sequestration, hyper-haemolytic and vasculo-occlusive crises.

Stewart and Nagel (2004), reported that blood transfusions in SCD are routinely done either as an interim intervention to correct anaemia or

hypovolemia, or as a chronic therapy to prevent stroke (Stuart & Nagel, 2004). Indications for transfusion therapy include: chronic splenic sequestration; severe or lasting aplastic crises; acute stroke; acute chest syndrome; and hemolytic episodes associated with malaria. Indications for chronic transfusions are stroke prevention and chronic pulmonary hypertension (Aliyu *et al.*, 2008; Kolapo & Vento, 2011; Stuart & Nagel, 2004). In order to prevent iron overload due to chronic transfusions, chelation may be indicated. Makani, Williams and Marsh (2007), noted that the use of blood transfusions in Sub-Saharan Africa is restricted due to the limited supply of blood, and potential HIV infection due to poor blood screening.

2.1.11 Treatment of Vaso-Occlusive Crises

Vaso-occlusive crises are also known as pain crises, and these crises are the major reason for visits to the emergency rooms by children with SCD. These painful episodes arise as a result of microvascular occlusions in bone marrow leading to necrosis (Stuart & Nagel, 2004). Common sites of pain include long bones, ribs, sternum spine and pelvis (Stuart & Nagel, 2004). In children younger than 3 years, acute hand-foot syndrome which involves painful swelling of the hands and feet is common. There are also abdominal painful episodes due to the micro-vascular occlusion in the mesenteric vessels coupled with decreased intestinal motility (Stuart & Nagel, 2004). Mild to moderate painful episodes may be treated at home using non-steroidal anti-inflammatory drugs (NSAIDs), or opioids. Severe pain episodes requiring hospitalization are

treated with continuous prenatal opioids.

2.1.12 Treatment of Infection

In a 2010 review of studies related to bacterial infections in children with SCD, Battersby, Knox-Macaulay and Carrol (2010) noted that a major reason for the increased susceptibility is due to splenic dysfunction (Battersby *et al.*, 2010). These authors acknowledged the need for further research to study the benefits of treatment such as penicillin prophylaxis and pneumococcal vaccines in Africa. Nevertheless, these authors recommended that when children with SCD present to the emergency room with a fever, a broad spectrum antibiotic should be started as soon as blood and urine specimen have been obtained for culture purposes.

2.1.13 Recommendations for Comprehensive SCD Treatment Programs

The decrease in morbidity and mortality among SCD children in low-resource countries is partly attributed to the presence of comprehensive care programs that include immunizations and vaccinations, prophylaxis therapy, vitamin supplements and patient/caregiver empowerment through education (Rahimy *et al.*, 2003). Cox *et al* (2011) and colleagues suggested that because SCD is associated with a high prevalence of malnutrition and stunting particularly among adolescents, comprehensive programs should also include nutrition education.

Rahimy *et al.* (2003) reported findings from an evaluation of a comprehensive

program in Benin that included provision of parent education about the SCD disease process and factors that may lead to acute SCD events. The education addressed topics such as the importance of hydration, providing adequate nutrition, spleen palpation, and other strategies to identify symptoms of acute SCD complications. Other interventions included providing recommended vaccinations and anti-pneumococcal and anti-malarial prophylaxis. Findings indicated a 78% reduction in the frequency and severity of SCD-related acute events, as well as improvement in general status and physical growth. Akinyanju *et al* (2005) reported findings from evaluation of a holistic program provided to 1223 SCD patients in Nigeria that included malaria prophylaxis, health and nutrition education, provision of folic acid and vitamin C, prompt attention for acute illnesses, and a support club for patients and their families. These authors reported a decrease in hospital admissions, mortality rate, and number of patients requiring blood transfusions over a 7 year period (Akinyanju *et al.*, 2005).

2.2 Empirical Studies

2.2.1 Mothers Coping Style to Financial Factors Associated with Child's SCD.

Mother's reactions to the stress of caring for a child with chronic illness depends on a variety of individual, family, and environmental factors (McCubbin & Patterson, 2003), such as individual interpretation of the crisis event, problem-solving skills (Han, Cho, Kim, & Kim, 2009), and the family's

resources including financial resources, extended family structure, educational level, availability of social support, and spirituality (McCubbin & Patterson, 2003; Sira & McConnell, 2008). McCubing and Patterson (2003) reported that, most mothers confront the financial stress that arises as a result of their children sickle cell disease through borrowing from friends and relatives. Folkman (1991) stated, while some women borrow money to take care of their children, some depend on their close relatives to take care of the financial stress like hospital bills and payment for drugs. Also, some studies has reported some women mostly widows and single mothers sale their properties to cope with hospital bills and buy drugs for their children (Miller *et al,* 2000; Wray & Sensky, 2004). However, some young single mothers resorted to prostitution to solve their financial stress including feeding (Coulson & Knibb, 2007).

2.2.2 Mothers Ways of Coping with Hospital/ Treatment Factors

Studies on stress experienced on treatments reported that working class mothers suffer greater part of the stress (Norberg, Lindbald & Boman, 2006; Simons *et al.*, 2007). Mothers report absenteeism from work while their children are being admitted as a result of SCD, it is also reported that the most difficult hospital stress experienced by mothers are waiting and keeping medical appointments (Jacob & Nathanson, 2016). While most mothers do not

keep appointments with doctors rather send representatives, others miss work or rather take excuse in order to meet up with their appointments with doctors. Reporting on how they cope with staffs attitude in the hospital, most mothers complain to heads of department on the attitude of their staffs while just few mothers could ignore hospital staffs ill behaviour to their children (Goldberg, Morris, Simmons, Fowler, & Levison, 1990).

Coulson & Knibb (2007), reported that some mothers blood group are similar to their children blood group, therefore alleviating them the stress for searching for blood donors in case of transfusion while most children suffering SCD has siblings with matchable blood groups and their mothers do not suffer much stress in providing blood donors.

2.2.3 Mothers Ways of Coping with Disease Factors

Schneider & Mannell (2006); reported that most mothers confronts crises through immediate medical attentions rather than seeking for spiritual prayers and complaining. Sira & McConnell (2008), reported that mothers in rural areas prefer traditional medicine to cure crises and infections that arise as a result of SCD. Some other studies reported that some religious mothers in urban areas prefer spiritual interventions when crises and infections attack their children suffering SCD.

CHAPTER THREE
MATERIALS AND METHODS

3.1 Study Design

The study is a hospital based cross-sectional study design. As with the case in every cross sectional study, exposure and effects are measured at the same time. In the present study, stress experienced by mothers is being measured alongside their copings strategies. Unlike in the case-control study or cohort study where recruitment into the study is done either by identifying cases and control or identifying exposed participants in order to follow them up, data on coping strategies in present study is collected from the sampled mothers of school aged children at the same time they are exposed to stress in order to determine the outcome at the particular time. Cross-sectional study gives a picture of the nature of stressors and adopted coping strategies by the mothers.

3.2 Description of Study Area

This study was carried out at Enugu State University Teaching Hospital (ESUTH) and University of Nigeria Teaching Hospital (UNTH), Enugu, Enugu State. The hospitals have different departments including peadiatrics department where Child Sickle Cell Disorder is treated. The hospitals experience influx of patients and this would be attributed to its affordability. Enugu is the capital of Enugu State Nigeria. It is located in southeastern part of Nigeria, with geographical coordinates of 6° 30N' 7° 30' E North. Despite its name meaning *hill top* in the Igbo language, Enugu lies at the foot of an

escarpment and not a hill. Enugu is located in the Cross River basin and the Benue trough and has the best developed coal in this area. Enugu is located in a tropical rain forest zone with a derived savannah. The city has a tropical savanna climate. Enugu's climate is humid and this humidity is at its highest between March and November. For the whole of Enugu State the mean daily temperature is 26.7 °C (80.1 °F). As in the rest of West Africa, the rainy season and dry season are the only weather periods that occurs in Enugu. The average annual rainfall in Enugu is around 2,000 millimeters (79 in), which arrives intermittently and becomes very heavy during the rainy season. Other weather conditions affecting the city include Harmattan, a dusty trade wind lasting a few weeks of December and January. Like the rest of Nigeria, Enugu is hot all year round.

According to the 2006 Nigerian census, the Enugu metropolitan area has an estimated population of 722,664 (NPC, 2006). The population of Enugu is predominantly Christian (Hansen and Curtis, 2008), as is the rest of southeastern Nigeria. Like the rest of Nigeria most people in Enugu speak English alongside the dominant language in the region. In Enugu, health care services can be obtained at several institutions including the ESUT (Enugu State University of Science and Technology) University of Nigeria Teaching Hospital, Psychiatric Hospital Enugu and the National Orthopaedic Hospital Enugu (NOHE), PMC (Peenok Medical Center), Hansa Clinic, Niger Foundation Hospital and Diagnostic Centre (Dede, Nwachukwu, Mbah, Ogbodo, Chiene-Nnaji, 2005).

3.3 Population of Study

The study population are mothers whose children were accessing treatment for SCD at University of Nigeria Teaching Hospital Enugu and Enugu State University Teaching Hospital (ESUTH). The population of these mothers were determined during the study. Each day the researcher and the research assistants visited these hospitals, they record the number of the women present and the study lasted one month for both hospitals. These hospitals were visited two times every week, identification numbers were given to the mothers in order not to count a mother twice. A total of 250 mothers were encountered at UNTH, while 210 mothers were seen at ESUTH in the course of the study.

3.4 Sample and Sampling Technique

3.4.1 Sample Size

The sample size was a total of two hundred and ninety-two (292) mothers selected from 460 mothers from UNTH and ESUTH. One hundred and fifty-four (154) were chosen from UNTH while one hundred and thirty-eight (138) were from ESUTH. The sample size was determined using Taro Yamane sample size formula (Appendix A).

3.4.2 Sampling Method

Systematic sampling method was used in selecting the study participants.

Using the formula for systematic random sampling to determine the systematic

sampling interval k, we have: k = N/n. Where N is the study population and n is the sample size.

Therefore for UNTH we have = 250/154 = 1.6 approximately 2.

For ESUTH we have = 210/138 = 1.5 approximately 2.

Therefore in selecting the sample size for both study population, the count started with the second person and the next person was the fourth person and it goes that way until the required sample sizes were obtained for both study population.

3.5 Instrument for Data Collection

A structured questionnaire was used to collect data from the respondents (Appendix B). The questionnaire has three sections: the first section sought information on the socio-demographic characters of the mothers. The second section sought information on stressors experienced by the mothers of school aged children with SCD. The information on stressors experienced by these mothers has six subsections; these subsections are stressors arising from: I. Hospital factors; II. Financial factors; III. Child factors; IV. Psychological factors; V. Disease Factors; VI. Family factors. The third Section sought information on the coping strategies adopted by the women to alleviate the stressors. The section also contains the relationship between stressors and marital status of the mothers and also the relationship between coping strategies and marital status. The questions in the questionnaire are clear and concise and have about 20 questions with multiple choice answers.

3.6 Validity of the Instrument

Face validity was used in validating the questionnaire. The questionnaire was carefully prepared by the researcher and was vetted by the supervisor and two experts in public health in relevance to the topic, contents, objectives and appropriateness of language. The corrections were used to modify the final draft.

3.7 Reliability of Instrument

Parallel reliability test was used to test the reliability of the instrument. Two sets of the questionnaire of equivalent contents were administrated to 20 women that were not part of the study at the same time (10 from Imo State University Teaching Hospital and 10 from Federal Medical Centre Owerri).

The two sets of results were ranked and Spearman's rank co-relation was used to calculate the co-relation co-efficient. The Spearman's rank co-relation co-efficient takes values between -1 and +1 (i.e. 0.1 to 1.0). Co-efficient of 0.70 – 1.0 is most acceptable and the co-efficient co-relation reliability of the instrument was 0.875 (Appendix C).

3.8 Method of Data Collection

Before the study started, permission was obtained from heads of institutions. Thereafter the researcher and research assistants sensitized the selected Mothers on the aim and importance of the study at the different Hospitals each

day of the study, since selection was done every day of the study. Four research assistants trained for the work administered the copies of questionnaire to the respondents. The literate mothers filled the questionnaires themselves and were cleared of doubts where they were confused. However, the questions were translated to local language for the non-literate mothers and their answers were filled by the research assistants. The questionnaire administration lasted between 3-5 minutes for each respondent.

3.9 Method of Data Analysis

Descriptive method was used to summarize the data variables. Frequency distribution table was constructed for all class variables and data were expressed as percentage of distribution. Chi-square test was used to analyse the level of significance of relationship between stressors and marital status and also between coping strategies and marital status, which was interpreted as calculated value > tabulated value at $P<0.05$.

3.10 Ethnical Clearance/Informed Consent

Ethical clearance was obtained from:

1. Futo School of Health Technology, Research Ethics Committee

2. Verbal informed consent was obtained from the mothers before being allowed to participate in the study.

CHAPTER FOUR

RESULTS AND DISCUSSION

In this chapter, Data from the field survey and results of analyses are presented in line with research questions and hypotheses.

4.1 Results

4.1.1 Socio–demographic Characteristics of Mothers of School-Aged Children with SCD accessing treatment in health facilities in Enugu Metropolis.

Table1: Socio–demographic Characteristics of Mothers of School-Aged Children with SCD accessing treatment in health facilities in Enugu Metropolis.

Parameters	Number of mothers	Percentage
Age (yrs)		
18 – 24	69	23.6
25 -30	79	27.2
31-34	55	18.8
35-40	49	16.7
Above 40	40	13.7
Total	292	100.0
Marital Status		
Married	200	68.5
Single	92	31.5
Total	292	100.0
Educational Status		
None	10	3.4
Primary	36	12.3
Secondary	146	50.0
Tertiary	100	34.3
Total	292	100.0
Number of school aged children suffering SCD per mother		
Mothers with one child suffering SCD	248	84.9
Mothers with more than one child suffering SCD	44	15.1
Total	292	100.0

Employment Status		
Govt. employee	78	26.7
Private employee	114	39.0
Traders	65	23.3
None	35	12.0
Total	292	100.0

The results of social demographic characteristics (table 4.1) shows that most of the mothers were between 25 – 30 years (27.2%), the least proportion of mothers were women above 40 years (13.7%). Also results of marital status, showed that 200(68.5%) were married mothers and 92(31.5%) mothers were either single mother or separated mothers.

Result on employment status reveals that 78(26.7%) women were government workers, 114(39.0%) were private workers, 65(22.3%) were traders and 35(12.0%) were not working. Also their educational status, reveals that half of the proportion of the women sampled had secondary school education 146(50%) and 100(34.3%) had tertiary education.

Result on the number of children suffering SCD per Mother was such, 248(84.9%) mothers had one child suffering SCD and 44(15.1%) mothers had more than one child suffering sickle cell disease.

4.1.2 Stressors experienced by mothers of school aged children with SCD in Enugu Metropolis

Table 2: Stressors experienced by mothers of school aged children with SCD in Enugu Metropolis

Impediments	Response from total number of 292 Mothers			
	Strongly agreed	Agreed	Disagreed	Strongly disagreed
Hospital Factors				
Inadequate numbers of hospital treating SCD	40 (13.6)	55(18.8)	107(36.6)	90(31.0)
Unsatisfactory services by health personnels	20(6.8)	42(14.3)	130(44.5)	100(34.4)
Inability of mothers to keep medical appointments	112(38.3)	140(47.9)	25(8.5)	15(5.3)
Financial Factors				
High cost of treatment/drugs	154(52.7)	71(24.3)	47(16.0)	20(7.0)
High cost of transportation to health facilities	110(37.6)	96(32.8)	53(18.1)	33(11.5)
High cost of special prescribed diet	82(28.0)	110(37.6)	70(23.9)	30(10.)
Child Factors				
Absenteeism from school due to recurrent illness	133(45.5)	60(20.5)	57(19.5)	42(14.5)
Low performance in academics	202(69.1)	50(17.1)	25(8.5)	15(5.3)
Poor growth and deformities	130(44.5)	80(27.3)	50(17.1)	32(11.1)
Psychological Factors				
Fear of occurrence of crisis at odd time	202(69.1)	50(17.1)	30(10.2)	10(3.6)
Thought of alternative means of treatment	92(31.5)	97(33.2)	83(28.4)	20(6.9)
Fear of having more children with SCD	240(82.1)	32(10.9)	15(5.1)	5(1.9)
Disease Factors				
Fear for re-curing crisis	292(100.0)	0(0.0)	0(0.0)	0(0.0)
Fear for sickness /infections	292(100.0)	0(0.0)	0(0.0)	0(0.0)
Fear for death	292(100.0)	0(0.0)	0(0.0)	0(0.0)
Family Factors				
Fear for rivalry/jealousy among the sick child's siblings	99(33.9)	109(37.3)	64(21.9)	20(6.9)
Reduces job performance in the family	47(16.0)	99(33.9)	73(25.0)	73(25.1)
Impacts on marriage as you give all the time to the sick child	39(13.3)	50(17.1)	70(23.9)	133(54.3)

Affects family social life	97(33.2)	103(35.2)	85(29.1)	7(2.5)

The stressors experienced by these women were investigated (Table 2). Results on hospitals factors shows that most proportion of the women 107(36.6%) disagreed and 90(31.0%) strongly disagreed to inadequate number of hospitals that treat SCD. For unsatisfactory services by health personnels, most women 130(44.5%) disagreed and 100(34.4%) strongly disagreed to unsatisfactory services by health personnels. While, 112(38.3%) and 140(47.9%) women strongly agreed and agreed respectively that they are unable to keep medical appointment.

Result regarding financial factors shows that, 154(32.7%) women and 71(24.3%) women strongly agreed and agreed respectively to high cost of treatments/drugs, while, 110(37.6%) women and 96(32.8%) women strongly agreed and agreed respectively to high cost of transportation to health facilities, while 82(28.0%) women and 110(37.6%) women strongly agreed and agreed respectively to high cost of special prescribed diet.

Results on child factors show that 133(45.5%) women and 60(20.5%) women strongly agreed and agreed respectively to absenteeism from school due to recurrent illness, 202(69.1%) women and 50(17.1%) women strongly agreed and agreed respectively to low performance in academics, and 130 (44.5%) and 80(27.3%) women strongly agreed and agreed respectively to poor growth deformities of children with SCD.

Results on psychological factors shows that 202 (69.1%) and 50 (17.1%) women strongly agreed and agreed respectively to the fear for occurrence of crisis at the odd time, 92 (31.3%) and 97(33.2%) women strongly agreed and agreed respectively to the thought for alternative means of treatment, 240(82.1%) and 32(10.9%) women strongly agreed and agreed respectively to the fear of having more children with SCD.

Results on Disease factors show that all the 292(100%) women strongly agreed to fear of recurring crisis, fear of sickness or infections and fear of death.

Results on family factors show that 99(33.9%) and 109(37.3%) women strongly agreed and agreed respectively to fear for rivalry/jealousy among the sick child siblings, 47(16.0%) and 99(33.9%) women strongly agreed and agreed respectively to reduced job performances in the family, 39(13.3%) and 50(17.1%) women strongly agreed and agreed respectively to impacts on marriage and 103(35.2%) strongly agreed and agreed respectively to effect of child SCD on family social life .

4.1.3 Coping strategies adopted by mothers of school age children with SCD accessing treatment in health facilities in Enugu Metropolis

Table 3: Coping strategies adopted by mothers of school age children with SCD accessing treatment in health facilities in Enugu Metropolis

	Coping Mechanism		N= 292
Variables	Confront (%)	Complain (%)	Ignore (%)
Hospital Factors	180(61.6)	72(24.6)	40(13.8)
Financial Factors	50(17.1)	202(69.1)	40(13.8)
Child Factors	210(71.9)	60(20.5)	22(7.6)
Psychological Factors	72(24.6)	140(47.9)	80(27.5)
Disease Factors	0(0.0)	292(100.0)	0(0.0)
Family Factors	180(61.6)	72(24.6)	40(13.8)

Results on hospital factors shows that confrontation was seen to be the prevalent coping mechanism adopted on hospital factors by 180 (61.6%) mothers, 202 (69.1%) women complained about impediments arising from financial factors, 210 (71.9%) confronted impediments associated with child factors, 140(47.9%) women complained about impediments associated with psychological factors and 180 (61.6%) women confronted impediments associated with family factors.

However, all the women complained about impediments associated with disease factors.

4.1.4 Association between Stressors and marital status of the mothers of school aged children with SCD accessing treatment in Enugu Metropolis

Table 4: Association between Stressors and marital status of the mothers of school aged children with SCD accessing treatment in Enugu Metropolis

Impediments/Marital Status	Stress Level N=292 Very stressful	Stressful	Non-stressful	X^2	P-Value
Hospital Factors*					
Married Mothers	50(25.0)	125(62.5)	25(12.5)		
Single Mothers	62(67.3)	20(21.7)	10(11.0)		
Total	112(38.4)	145(49.7)	35(11.9)	50.83	0.000
Financial Factors*					
Married Mothers	122(61.0)	58(29.0)	20(10.0)		
Single mothers	72(78.2)	15(16.3)	5(5.5)		
Total	194(66.4)	73(25.0)	25(11.6)	8.441	0.014
Child Factors*					
Married Mother	120(60.0)	69(34.5)	11(5.5)		
Single Mothers	80(86.9)	12(13.1)	0(0.0)		
Total	200(68.5)	81(27.7)	11(3.8)	27.12	0.000
Psychological Factors*					
Married Mothers	146(73.0)	50(25.O)	4(2.0)		
Single Mothers	69(75.0)	17(18.4)	6(6.6)		
Total	215(73.6)	67(22.9)	10(3.5)	4.781	0.091
Disease Factors					
Married Mothers	200(100.0)	0(0.0)	0(0.0)		
Single Mothers	92(100.0)	0(0.0)	0(0.0)		
Total	292(100.0)	0(0.0)	0(0.0)	0.000	1.000
Family Factors*					
Married Mothers	49(24.5)	71(35.5)	80(40.0)		
Single Mothers	42(45.6)	25(27.2)	25(27.2)		
Total	91(27.7)	96(32.9)	105(39.4)	3.780	0.151

*** showed significant difference**

The association between stressors and marital status of the mothers of school aged children with SCD is shown on Table 4. 50(25%) married mothers and 62 (67.3%) single mothers saw hospital factors as very stressful, while 25% (12.5%) married and 10(11.0%) single mothers saw hospital factors as not stressful. These is a significant association between hospital factors and marital status of mothers of school aged children with SCD (X^2 = 50.83, P = 0.000, df= 2).

Similarly on financial factors, 122 (61.0%) married mothers and 72(78.2%) single mothers saw financial factors as very stressful while, 20(10.0%) married mothers and 5(5.5%) single mothers saw financial factors as not stressful. There is a significant association between financial factors and marital status of mothers of school aged children with SCD (X^2 = 8.441, P = 0.014, df=2).

120 (60.0%) married mothers and 80 (86.9%) single mothers saw child factors as very stressful while only 11(5.5%) married mothers saw child factors as not stressful. There is a significant association between child factors and marital status of mothers of school aged children with SCD (X^2 = 27.12, P = 0.000, df=2). There is also a significant association between psychological factors and marital status of mothers of school aged children with SCD (X^2 = 4.781, P =0.091, df=2) and between family factors and marital status of the women (X^2 = 3.780, P = 0.151, df=2).

However, there was no significant association between disease factors and marital status of women (X^2 = 0.000, P = 1.000, df=2) as all the mothers of school aged children with SCD see disease factors as being very stressful.

4.1.5 Association between coping mechanism and marital status of the mothers of school aged children with SCD accessing treatment in health facilities in Enugu Metropolis.

Table 5: Association between coping mechanism and marital status of the mothers of school aged children with SCD accessing treatment in health facilities in Enugu Metropolis.

Variables/Marital Status	N=292	Coping Mechanism			X^2	P-Value
		Confront	Complain	Ignore		
Hospital Factors*						
Married Mothers		133(66.7)	42(21.0)	25(12.3)		
Single Mothers		47(51.0)	30(32.6)	15(16.4)		
Total		180(61.6)	72(24.7)	40(13.7)	6.490	0.039
Financial Factors*						
Married Mothers		35(17.5)	132(66.0)	33(16.5)		
Single mothers		15(16.3)	70(76.0)	7(7.7)		
Total		50(17.1)	202(69.2)	40(13.7)	4.610	0.099
Child Factors*						
Married Mother		160(80.0)	30(15.0)	10(5.0)		
Single Mothers		50(54.3)	30(32.6)	12(13.1)		
Total		210(71.9)	60(20.5)	22(7.6)	20.51	0.000
Psychological Factors*						
Married Mothers		52(26.0)	120(60.0)	28(14.0)		
Single Mothers		20(21.7)	20(21.7)	52(48.6)		
Total		72(24.7)	140(47.9)	80(27.4)	28.51	0.000
Disease Factors						
Married Mothers		0(0.0)	200(100.0)	0(0.0)		
Single Mothers		0(0.0)	92(100.0)	0(0.0)		
Total		0(0.0)	292(100.0)	0(0.0)	0.000	1.000
Family Factors*						

Married Mothers	140(70.0)	50(25.0)	10(5.0)		
Single Mothers	40(43.4)	22(23.9)	30(32.7)		
Total	180(61.6)	72(24.7)	40(13.7)	23.21	0.000

*** showed significant difference**

Relationship between coping mechanism and marital status of the mothers of school aged children with SCD is presented in table 5. Results on hospital factors show that majority of the women both married 133(65.0%) and single 47(51.0%) confront hospital factors. 42 (21.0%) married mothers and 30 (32.6%) single mothers complained, while 25 (12.3%) married and 15 (16.4%) single mothers ignored hospital factors. There is a significant association between hospital coping mechanism and marital status of the women (X^2 = 6.490, P= 0.039, df= 2).

On financial coping mechanism, 132 (66.0%) married mothers and 70(76.0%) single mothers complain about financial stress factors. 35 (17.5%) married mothers and 15 (16.3%) single mothers confront financial factors, while 33 (16.5%) married mothers and 7(7.7%) single mothers ignore financial factors. This also shows a significant relationship between financial coping mechanism and marital status of the women (X^2 = 4.610, P = 0.099, df=2).

Results on child factors shows that 80% of married mothers confront child stress factors and 54.3% of single mothers also confront child factors. There is a significant relationship between child factor coping mechanism and marital status of mothers (X^2 = 20.51, P= 0.000, df = 2). Also a significant relationship

was seen between psychological coping mechanism and marital status of mothers (X^2 = 28.5, P = 0.000, df = 2), as majority 120 (60.0%) of married mothers complain about psychological factors while most single 52(48.6) mothers ignore psychological factors. There is a significant relationship between family factors coping mechanism and marital status of mothers (X^2 = 23.2, P = 0.000, df = 2).

However in this study, no significant relationship occurred between disease coping mechanism and marital status of mothers, as all the mothers complain about disease factor (X^2 = 0.000, P = 1.000, df = 2).

4.2 Discussion

Sickle Cell Disease sufferers, as well as their caregivers are faced with several factors such arising from hospitals, inadequate funds, disease/illness, psychological, child factors as well as family factors. Hence, parents or caregivers of these children tend to have worse health related quality of life, compared to those without SCD children which impacts negatively on their behavior and self-esteem (Brown *et al*, 2010; Van Den Tweel, Hatzmann and Ensike, 2008).

In this study, the socio-demographic characteristics of mothers of school aged children with SCD were similar to those of other studies carried out in other parts of Nigeria (Ohaeri and Shokunbi, 2002; Tunde-Ayinmode, 2007). Whilst only about half of the mothers had secondary school education, 34.3% completed tertiary education, 12.3% has only primary education and 3.4% did

not have any formal education. In addition, the socio-economic stratification of the mothers was similar to parents of children with other illness in south western Nigeria (Ohaeri and Shokunbi, 2002; Adegoke, Dedeke and Oyelami, 2010; Ogunlesi, Runsewe-Abiodun and Olanrewaju, 2009) except having associated mothers in present study with number of children suffering SCD. There is therefore no reason to suggest that the participants involved in this study differed in socio-demographic characteristics from the general population in our environment other than the illness variables.

This study investigated six basic factors that affect mothers of children suffering SCD, the first was the hospital factors which comprised of; unavailability of hospitals treating SCD, unsatisfactory services by health personnels and mothers inability to keep medical appointments. These were big challenges to mother mothers, especially the single mothers who saw them as very stressful events unlike most married mothers who saw hospital factors as just stressful events. The discrepancy existing on hospital factors between married and single mothers would be given to the fact that, some married mothers involve their husbands in the treatment and taking care of the children with SCD, as a result reducing the impediments facing them. More than half of the mothers agreed that hospital factors are coped with by confronting the situation. They confront the situation either by, getting suitable hospitals that treat SCD, trying their best to keep medical appointments and reporting medical personnels who have not discharged their duties well. These are consistent with the work of Wonkam *et al* (2013), who reported varying

ways mothers of children with SCD confront hospital stress factors.

The financial factors facing mothers is very high in this study. Two third of the mothers reported that the expenses of their child's illness were very high. These expenses include, cost of treatments and drugs, cost of transporting the sick child to hospitals and cost of providing special diet for the child. Considering the expenses these mother undergo, it must be stressful paying the child's hospitals bills, catering for the family's basic needs such as, food, school fees, clothing and house rents. Like hospital stress factors, financial stress factors are high among single mothers. The reason could be, as single mothers, they try to balance the financial needs of the house in order to provide all the basic needs. Since they do not have spouses, all the financial burdens in the house are on them, it must be very stressful settling these financial burdens.

In Nigeria, like many other developing countries, national programme on health insurance are not functioning adequately, making caring for a child with chronic illness such as SCD a great financial burden and stress to their care givers especially single mothers (Adegoke and Kuteyi, 2012). The predominant financial coping mechanism adopted by the mothers was to complain. A greater number of the mothers express complaint through, anger, self blame, weep and prayers. Most times, some single mothers complain to their relations, who may help pay off their hospital bills. However, some rich mothers confront their financial stress, because they could afford the cost of treatments and hospital bills.

Child factors which occur in the form of frequent school absenteeism as a

result of re-current crisis, low performance in school and poor growth/deformities were another major stress to the mothers as shown in this study. Most mothers confronted child stress factors through avoiding re-current crisis by providing the children with medications promptly and providing them with adequate nutrition. Some develop adequate and concrete educational plan that is less tedious and bearable for the child's condition.

Another important factor which has a serious health concern to mothers is the psychological factors. Psychological factors were based mainly based on fear. The fear of occurrence of crisis at odd times, thought of alternative means treatment and fear for having more children with SCD, all these weigh in the minds of mothers, who subsequently suffered depression and other health related problems. This is consistent with a study on psychosocial burden of SCD on their mothers in USA, where they found sickle cell patients and their care givers experience more depressive symptoms than the control (Moskowitz *et al*, 2007). Similar studies in developing countries like Nigeria also agreed with this high depression among caregivers of patients with chronic illness (Ohaeri and Shokunbi, 2002; Tunde-Ayinmode, 2007). Most Mothers have coped differently with psychological stress by avoiding re-occurrence of crisis at odd times through giving prompt medications and being always prepared in case of emergencies. Some made up their minds not to give birth again, just to relief them the fear of bearing another child with SCD. Greater number of mothers complains about their psychological stress. They do this to seek people's opinions and counsels, in order to know how best to deal with fear and

other psychological stress. However, this study recorded some mothers who just ignore psychological stress associated with child SCD. Some of them who ignore psychological factors are too religious or people who believe in divination and God's intervention in their case.

All the mothers in this study strongly agree that disease factors which were seen as fear of re-occurring crisis, fear of sickness/infections and fear for death were very stressful. Some mothers reported that at some stage in their child's conditions, they gave up hope waiting for miracle to happen. At this point, the child's sickness must have sapped them all the money they had, and they were left with no other option than death. Reporting on how they coped with it, they revealed that there was no way to cope with it but to complain. Some said you can only lament, cry, express anger and depression, you can't fight death or ignore your child as she/ he dies in pains. A study in Nigeria on mothers stress in SCD shows that some mothers complain about disease stress factors rather than confronting or ignoring them (Wonkam *et al* , 2013).

Family social life and interaction have been described as significant areas of social life for SCD patients and their families (Ohaeri and Shokunbi, 2002). In this study, most mothers give all their time to their sick children and agreed that due to time and are given to their sick children, it has given rise to jealousy among other children, reducing their job performance in the house, impacting on their marriage and affecting the family's entire social life. The way mothers relate with their ill children generally generates feelings of neglect in other members of the family especially the siblings of the ill child and this is a

major factor in family dysfunction (Tunde-Ayinmode, 2007). This neglect especially when experienced too frequently has been described as risk factors in the psychopathology of psychosocial problems in chronic physical illness (Dinleyici & Dagli, 2018). However, these factors are confronted by majority of mothers. In this study, mothers try to balance the feelings among other siblings. They buy things for other children, so as to remove the feelings of neglect in them. Some mothers make out time for their families to balance the lost time in caring for their ill children. This is consistent with the study of Adegoke and Kuteyi (2012), which reported mothers confronting family social factors associated with child SCD.

CHAPTER FIVE
CONCLUSION AND RECOMMENDATION

5.1 CONCLUSION

This study has shown that both married and single mothers of children with SCD experience significant impediments which they adopted various ways of coping with them. It is therefore important that clinicians and policy makers provide the necessary psychological care and support to these children so as to assuage the level of stress their mothers undergo.

5.2 Recommendations

Based on the findings of this study, it is recommended that:

1. Managements of hospitals should provide care centers that will offer psychological supports to the mothers of children with SCD. This is to enable them brace up for the emotional and psychological stress that is associated with their children's disease.
2. Government should develop special scheme that helps in the caring of people living with SCD, to alleviate the financial stress on the mothers or care givers.
3. Mothers of Children with SCD are advised to learn a better way of marrying the care for their sick children and their duties in the family, so that other members of the family do not feel neglected.

REFERENCES

Abioye-Kuteyi, E. A., Oyegbade, O., Bello, I., & Osakwe, C. (2009). Sickle cell knowledge, premarital screening and marital decisions among local government workers in Ile-Ife, Nigeria. *African Journal of Primary Health Care & Family Medicine,* 1(1), 53–57.

Adegoke, S. A., Dedeke, I. O. F., & Oyelami O.A. (2010). Childhood injuries in Ilesha, South-Western, Nigeria: Causes, Patten and Outcome. West *African Journal of Medicine, 29(4), 253-258.*

Adegoke, S. A., & Kuteyi, E. A. (2012). Psychological Burden of Sickle Cell Disease on Family, Nigeria. *African Journal of Primary Health Care & Family Medicine, 4(1), 1-6.*

Afolayan, J. A., & Jolayemi, F. T. (2011). Parental attitude to children with sickle cell disease in selected health facilities in Irepodun Local Government, Kwara State, Nigeria. *Studies on Ethno-Medicine, 5(1), 33–40.*

Ahmed, S., Atkin, K., Hewison, J., & Green, J. (2006). The influence of faith and religion and the role of religious and community leaders in prenatal decisions for sickle cell disorders and thalassaemia major. *Prenatal Diagnosis,* 26(9), 801–809.

Akinyanju, O. O., Otaigbe, A. I., & Ibidapo, M. O. (2005). Outcome of holistic care in Nigerian patients with sickle cell anaemia. *Clinical and Laboratory Haematology*, 27(3), 195–199.

Aliyu, Z. Y., Kato, G. J., Taylor, Jt., Babadoko, A., Mamman, A. I., Gordeuk, V. R., (2008). Sickle cell disease and pulmonary hypertension in Africa: A global perspective and review of epidemiology, pathophysiology, and management. *American Journal of Hematology*, 83(1), 63–70.

Anie K. A. (2005). Psychological complications in sickle cell disease. *British Journal of Hematology*, 129(6), 723-729.

Anie, K., Egunjobi, F. E., & Akinyanju, O. O. (2010). Psychosocial impact of sickle cell disorder: Perspectives from a Nigerian setting. *Global Health*, 62.

Animasahun, B. A., Akitoye, C. O., & Njokanma, O. F. (2009). Sickle cell anaemia: Awareness among health professionals and medical students at the Lagos University Teaching Hospital, Lagos. *Nigerian Quarterly Journal of Hospital Medicine*, 19(4), 195–199.

Aniowu, E, Watford, D, Brozovic, M, and Kirkwood, B. (1981). Sickle cell disease in a British Urban Community. British Medical Journal, 282, 285-296.

Aygun, B., & Odame, I. (2012). A global perspective on sickle cell disease. Pediatric Blood & Cancer, 59(2), 386–390. http://dx.doi.org/10.1002/pbc.24175. PubMed

Balogun, R. A., Obalum, D. C., Giwa, S. O., Adekoya-Cole, T. O., Ogo, C. N., & Enweluzo,G. O. (2010). Spectrum of musculo-skeletal disorders in sickle cell disease in Lagos, *Nigeria. Journal of Orthopaedic Surgery and Research,* 5, 2.

Battersby, A. J., Knox-Macaulay, H. H., & Carrol, E. D. (2010). Susceptibility to invasive bacterial infections in children with sickle cell disease. *Pediatric Blood & Cancer,* 55(3), 401–406.

Breslay, N, (1983). Care of disable children and women's time use. Medical Care. 21, 620-629.

Brown, B., Okereke, J., Lagunju, I., Orimadegun, A., Ohaeri, J., & Akinyinka, O. (2010). Burden of health-care of carers of children with sickle cell disease in Nigeria. Health Social Care Community. 18, 289-295.

Chakravorty, S., & Williams, T.N. (2015). Sickle cell disease: A neglected chronic disease of increasing global health importance, Archives of Disease in Childhood, 100, 48-53.

Coulson, N. S., & Knibb, R. C. (2007). Coping with food allergy: Exploring the role of the online support group. *Cyber Psychology & Behavior*, 10, 145–148.

Cox, S. E., Makani, J., Fulford, A. J., Komba, A. N., Soka, D., Williams, T. N. (2011). Nutritional status, hospitalization and mortality among patients with sickle cell anemia in Tanzania. *Haematologica*, 96(7), 948–953.

Diggs, L & Flower, E. (1971). Sickle cell anemia in the home environment. *Clinical Pediatric 10, 697-700.*

Dinleyci, M. & Dagli, F.S. (2018). Evaluation of quality of life of healthy siblings of children with chronic disease. Turkish Pediatric Association, 53(4), 205-213.

Durham, W. H. (1991). Coevolution: Genes, Culture and Human diversity, Standford University Press.

Fleming, A.P, et al (1979), Abnormal haemoglobins in the Sudan Savannah of Nigeria. Prevalence of haemoglobins and relationships between sickle cell trait, malaria and survival. Annals of tropical medicine and parasitology. 73, 161-

172.

Goldberg, S., Morris, P., Simmons, R. J., Fowler, R. S.,& Levison, H. (1990). Chronic illness in infancy and parenting stress: A comparison of three groups of parents. Journal of Pediatric Psychology, 15,347–358.

Han, H. R., Cho, E. J., Kim, D., & Kim, J. (2009). The report of coping strategies and psychosocial adjustment in Korean mothers of children with cancer. Psycho-Oncology, 18, 956–964

Hopia, H., Tomlinson, P. S., Paavilainen, E. & Astedt-Kurki, P. (2004). Child in hospital: Family experiences and expectations of how nurses can promote family health. Journal of Clinical Nursing, 14(2), 212–222.

Ikefuna, A. N. & Emodi, I. J. (2007). Hospital admission of patients with sickle cell anaemia pattern and outcome in Eugu area of Nigeria. Nigerian Journal of Clinical Practice, 10(1), 24–29.

Jacob, E. & Nathanson, J.D. (2016). Barriers to Care and Quality of Primary Care Services in Children with Sickle Cell Disease. *Journal of Advanced Nursing*, 72(6), 1417-1429.

Kabiti I.A 2008. Anthropometric Profiles of Homozygous Sickle Cell Children in North–western Nigeria. *AJOL*,11; 2.

Kafando, E., Sawadogo, M., Cotton, F., Vertongen, F., & Gulbis, B. (2005). Neonatal screening for sickle cell disorders in Ouagadougou, Burkina Faso: A pilot study. Journal of Medical Screening, 12(3), 112–114.

Kolapo, K. O., & Vento, S. (2011). Stroke: A realistic approach to a growing problem in sub-Saharan Africa is urgently needed. Tropical Medicine & International Health, 16(6), 707–710.

Komba, A. N., Makani, J., Sadarangani, M., Ajala-Agbo, T., Berkley, J. A., Newton, C. R., et al. (2009). Malaria as a cause of morbidity and mortality in children with homozygous sickle cell disease on the coast of Kenya. Clinical Infectious Diseases, 49(2), 216–222

Kushnir T, and Kasan, R. (1995). Major sources of stress among Women Managers, Clerical Workers and Working Single Mothers: Demand vs Resources. Public Health Review, 20, 215-229.

Moskowitz, J.T., Butensky, E., Harmatz, P., Vichinsky, E., Heyman M.B., Acree, M., Wrubel, J., Wilson, L., & Folkman, S. (2007). Caregiving time in sickle cell disease: psychological effects in maternal caregivers. Paediatric Blood Cancer, 48(1), 64-71.

Makani, J., Williams, T. N., & Marsh, K. (2007). Sickle cell disease in Africa: Burden and research priorities. Annals of Tropical Medicine and Parasitology, 101(1),3–14.

McBride, A.B, & Black, K.N, (1984). Differences that suggest female investment in, and male distance from, children sex roles, 10, 231-246.

McCubbin, H. I., & Patterson, J. M. (2003). The family stress process: The double ABCX model of adjustment and adaptation. In H. I. McCubbin, M. B. Sussman, &J. M. Patterson (Eds.), Social stress and the family (pp.7–37). New York, NY: Haworth.

Miller, R., Sabin, C. A., Goldman, E., Clemente, C., Sadowski,H., Taylor B., & Lee, C. A. (2000). Coping styles in families with haemophilia. Psychology, Health & Medicine, 5, 3–12.

Modell, B., & Darlison, M. (2008). Global epidemiology of haemoglobin disorders and derived service indicators. Bulletin of the World Health Organization, 86(6),480–487.

Noll RB, McKellop, JM, Vannatta KM, Kalinyak K 1998.Child-rearing practices of Primary Care Givers of Children with Sickle Cell Disease: The Perspective of Professionals and Care Givers. *Journal of Paediatric Psychology*, 23(2): 131-140.

Norberg A. L., Lindbald, F., & Boman, K. K. (2006). Support-seeking, perceived support and anxiety in mothers and fathers after children's cancer treatment. Psycho-Oncology, 15, 335–343.

Obaro, S. (2010). Preventable deaths in sickle-cell anaemia in African children. Lancet, 375(9713), 460.

Odunvbun, M. E., Okolo, A. A., & Rahimy, C. M. (2008). Newborn screening for sickle cell disease in a Nigerian hospital. Public Health, 122(10), 1111–1116.

Ogunlesi,T., Runsewe-Abiodun, I., & Olanrewaju, D. (2009). Health care seeking behavior for childhood illnesses in a resource-poor setting. *Jounal of Paediatric Child Health, http://dx.doi.org/10.111/j.1440-1754.2009.01677.x*

Ohaeri, J.U., & Sokunbi, W.A. (2002). Psychosocial burden of sickle cell disease on care givers in a Nigerian setting. Journal of National Medical Association, 94(12): 1058-1070.

Ohene-Frempong, K., Oduro, J., Tetteh, H., & Nkrumah, F. K. (2008). Screening newborns for sickle cell disease in Ghana. Pediatrics, 121(S120).

Okpuzor, J., Adebesin, O., Ogbunugafor, H., & Amadi, I. (2008). The potential of medicinal plants in sickle cell disease control: A review. International Journal of Biomedical and Health Sciences, 4(2), 47–55.

Olatawura, M. P. (1976). Sickle cell disease- The psychological Aspects. *African Journal of Psychiatry, 3, 373–377.*

Prihartono N.A., Fitriyani, F., Riyadina, W. (2018). Cardiovascular Disease Risk Factors Among Blue and White-collar Workers in Indonesia. Acta Med Indones, 50(2), 96-103

Quinn, C. T., Rogers, Z. R., McCavit, T. L., & Buchanan, G. R. (2010). Improved survival of children and adolescents with sickle cell disease. Blood, 115(17), 3447–3452

Rahimy, M. C., Gangbo, A., Ahouignan, G., Adjou, R., Deguenon, C., Goussanou, S.,et al. (2003). Effect of a comprehensive clinical care program on disease course in severely ill children with sickle cell anemia in a sub-Saharan African setting. Blood, 102(3), 834–838.

Rance, J.C & Skirton H. (2019). An integrative review of factors that influence reproductive decisions in women with sickle cell disease. *Journal of Community Genetics* 10(2), 161-169.

Rwezaula, S.S (2010). Neonatal screening for haemoglobinopathies as Muhimbili National Hospital. Dar Es Salaam: Muhimbili University of Health and Allied Sciences.

Schenck-Gustafsson, K. & Orth-Gomer, K. (2000). Job stress and the occupational gradient in coronary heart disease risk in women. The Stockholm Female Coronary Risk Study. Social Science Medicine, 51(4), 481-489.

Schneider, M. A., & Mannell, R. C. (2006). Beacon in the storm: An exploration of the spirituality and faith of parents whose children have cancer. Issues in Comprehensive Pediatric Nursing, 29, 3–24.

Serjeant, G., & Ndugwa, C. (2004). Sickle cell disease in Uganda: A time for action. East African Medical Journal, 80(7), 384–387.

Simons, L., Ingerski, L. M., & Janicke, D. M. (2007).Social support, coping and psychological distress in mothers and fathers of pediatric transplant candidates: A pilot study. Pediatric Transplantation, 11,781–787.

Sira, N., & McConnell, M. (2008). Attitudes toward spirituality and child life services. Journal of Pastoral Counseling, 43, 30–47.

Stuart, M. J., & Nagel, R. L. (2004). Sickle-cell disease. Lancet, 364(9442), 1343–1360.

Tshilolo, L., Kafando, E., Sawadogo, M., Cotton, F., Vertongen, F., Ferster, A., et al.(2008). Neonatal screening and clinical care programs for sickle cell disorders in sub-Saharan Africa: Lessons from pilot studies. Public Health, 122(9), 933–941.

Tunde-Ayinmode M. F. (2007). Psychosocial impact of sickle cell disease on mothers of affected children seen at University of Ilorin Teaching Hospital, Ilorin, Nigeria. *East Africa Medical Journal, 84(9), 410–419.*

Van Den Tweel, X.W., Hatzmann, J., & Ensike, E. (2008). Quality of life of female carers of children with Sickle cell disease: A survey. Heamatologica 93(4), 588–593

Verduzco, L. A., & Nathan, D. G. (2009). Sickle cell disease and stroke. Blood, 114(25), 5117–5125

Wambebe, C., Khamofu, H., Momoh, J. A., Ekpeyong, M., Audu, B. S., Njoku, O. S., et al.(2001). Double-blind, placebo-controlled, randomised cross-over clinical trial of NIPRISAN in patients with Sickle Cell Disorder. Phytomedicine, 8(4), 252–261.

Weatherall, D. J. (2011). The challenge of haemoglobin opathies in resource-poor countries. British Journal of Haematology.

Wierenga, K. J., Hambleton, I. R., & Lewis, N. A. (2001). Survival estimates for patients with homozygous sickle-cell disease in Jamaica: A clinic-based population study. Lancet, 357(9257), 680–683.

Wonkam, A., Mba, C.Z., Mbanya, D., Ngogang, J., Ramesar, R. & Angwafo III F.F. (2013). Psychosocial Burden of Sickle Cell Disease with an Affected Child in Cameroon. *Journal of Genetic Counselling,* 23(2),

World Health Organization (2006) Sickle Cell Anaemia. WHO Fifty-Ninth World Assembly A59/9, Geveva.

World Health Organization (2006). Management of birth defects and haemoglobin disorders: Report of a joint WHO-March of Dimes meeting, Geneva, Switzerland, 17–19 May 2006.

Wray, J., & Sensky, T. (2004). Psychological functioning in parents of children undergoing elective cardiac surgery. Cardiology in the Young, 14, 131–139.

APPENDIX A

SAMPLE SIZE DETERMINATION

A sample size of 292 women was determined from 250 mothers whose children were taking treatment at University of Nigeria Teaching Hospital Enugu and 210 mothers whose children were also taking treatment at Enugu state University Teaching Hospital (ESUTH) giving a total of 460 mothers. The sample size was determined using Taro Yamane formula.

Thus, $n = \frac{N}{1+N(e)^2}$

Where N= Whole Population that is from
n = Sample size that is required from the population under study
e^2 = the precision or sampling error which is 0.05

For UNTH

N = 250
e^2 = 0.05
n =?

Using $n = \frac{250}{1+250(0.05 \times 0.05)}$ = 153.8 ≅ 154.

For ESUTH

N = 210
e^2 = 0.05
n = ?

Using n = $\frac{210}{1+210\ (0.05 \times 0.05)}$ = 137.7 ≅ 138.

$\Sigma n_i + n_{ii}$ = 154 + 138 = 292.

APPENDIX B

INSTRUMENT FOR DATA COLLECTION

A QUESTIONNAIRE FACTORS IN COPING PATTERN OF MOTHERS OF SCHOOL AGED CHILDREN WITH SCD IN ENUGU METROPOLIS.

Date .....
Please tick in the box that suits your answer
SECTION A: Socio-Demographic characteristics of mothers of school Age children with SCD.

1. **Age(years)**

Less than 18 ☐, 18-24 ☐, 25-30 ☐ , 31-34 ☐ , 35-40 ☐
Above 40 ☐

2. **Marital status**:

Married ☐ single ☐

3. **Level of education**:

None ☐ , Primary Only ☐ , Secondary ☐
Up to Tertiary ☐

4. **Number of school aged children suffering SCD per mother**:

One child ☐ , more than one child ☐

5. **Employment status**

Govt. Employed ☐ , Private worker ☐ , Trader ☐
None ☐

SECTION B: IMPEDIMENTS EXPERIENCED BY THE MOTHERS OF SCHOOL AGED CHILDREN WITH SCD IN ENUGU METROPOLIS.

What are the impediments associated with the following factors:

I. HOSPITAL FACTORS:

6. Unavailability of hospitals that treat SCD

Strongly agree ☐ , Agree ☐ , Disagree ☐ , Strongly disagree ☐

7. Unsatisfactory services by health personnel

Strongly agree ☐ , Agree ☐ , Disagree ☐ , Strongly disagree ☐

8. Inability to keep medical appointments

Strongly agree ☐ , Agree ☐ , Disagree ☐ , Strongly disagree ☐

II. FINANCIAL FACTORS

9. High cost of treatment/drugs.

Strongly agree ☐ , Agree ☐ , Disagree ☐ , Strongly disagree ☐

10. High cost of transport to health facilities

Strongly agree ☐ , Agree ☐ , Disagree ☐ , Strongly disagree ☐

11. High cost of special prescribed diet.

Strongly agree ☐ , Agree ☐ , Disagree ☐ , Strongly disagree ☐

III. CHILD FACTORS

12. Absenteeism from school due to recurrent illness.

Strongly agree ☐ , Agree ☐ , Disagree ☐, Strongly disagree ☐

13. Low performance in academics.

Strongly agree ☐ , Agree ☐ , Disagree ☐ , Strongly disagree ☐

14. Poor growth and deformities.

Strongly agree ☐ , Agree ☐ , Disagree ☐ , Strongly disagree ☐

IV. PSYCHOLOGICAL FACTORS:

15. Fear of occurrence of crisis of odd time.

Strongly agree ☐ , Agree ☐ , Disagree ☐ , Strongly disagree ☐

16. Thoughts of alternative means of treatments.

Strongly agree ☐ , Agree ☐ , Disagree ☐ , Strongly disagree ☐

17. Fear of having more children with SCD.

Strongly agree ☐ , Agree ☐ , Disagree ☐ , Strongly disagree ☐

V. DISEASE FACTORS

18. Fear of re-occurring crisis

Strongly agree ☐ , Agree ☐ , Disagree ☐ , Strongly disagree ☐

19. For sickness/infection.

Strongly agree ☐ , Agree ☐ , Disagree ☐ , Strongly disagree ☐

20. For death.

Strongly agree ☐ , Agree ☐ , Disagree ☐ , Strongly disagree ☐

VI. FAMILY FACTORS

21. Fear for rivalry/jealousy among the sick child siblings.

Strongly agree ☐, Agree ☐, Disagree ☐ , Strongly disagree ☐

22. Reduces job performance in the family

Strongly agree ☐ , Agree ☐, Disagree ☐ , Strongly disagree ☐

23. Impacts on marriage as you give all the time to the sick child.

Strongly agree ☐ , Agree ☐ , Disagree ☐ , Strongly disagree ☐

24. Affects family social life.

Strongly agree ☐ , Agree ☐ , Disagree ☐ , Strongly disagree ☐

VII. ASSOCIATION BETWEEN IMPEDIMENTS CONFRONTING MOTHERS AND MARITAL STATUS OF MOTHERS OF SCHOOL.

	Stress level		
Impediments/ marital status	**Very stressful**	**Stressful**	**Non stressful**
Hospital factors			
Married			
Single			
Financial factor			
Married			
Single			
Child Factors			
Married			
Single			
Psychological Factor			
Married			
Single			
Disease factor			
Married			
Single			
Family factor			
Married			
Single			

SECTION C: COPING MECHANISM BY MOTHERS OF SCHOOL AGED CHILDREN WITH SCD IN ENUGU METROPOLIS

26. How do you cope with the following factors?

I. Hospital Factors: Confront ☐ , Complain ☐ , Ignore ☐
II. Financial Factors: Confront ☐ , Complain ☐ , Ignore ☐
III. Child Factors: Confront ☐ , Complain ☐ , Ignore ☐
IV. Psychological Factors: Confront ☐ , Complain ☐ , Ignore ☐
V. Disease Factors: Confront ☐ , Complain ☐ , Ignore ☐
VI. Family Factors: Confront ☐ , Complain ☐, Ignore ☐

27. ASSOCIATION BETWEEN COPING MECHANISM AND MARITAL STATUS OF THE MOTHER OF SCHOOL AGED CHILDREN WITH SCD

	Coping mechanism		
FACTORS/MARITAL STATUS	**Confront**	**Complain**	**Ignore**
Hospital Factors			
Married mothers			
Single mother			
Financial factors			
Married mothers			
Single mothers			
Child factor			
Married mother			
Single mother			
Psychological factors			
Married mothers			
Single mothers			
Disease factor			
Married mother			
Singles mother			
Family factor			
Married mothers			
Singles mothers			

APPENDIX C

CO-EFFICIENT CO–RELATION RELIABILITY OF INSTRUMENT

Marks of responses From UNTH (x)	Marks of Responses ESUTH(d)	Rank ($x = d_x$)	Rank ($y = d_y$)	$d = d_x - d_y$	d^2
75	78	2	1	1	1
50	65	3.5	3	+0.5	0.25
50	60	3.5	4	-0.5	0.25
45	50	5	5	0	0
80	70	1	2	-1	1
					2.50

Therefore using the Spearman's Rank Co-relation

We have = $r_s = 1 - \frac{6 \sum_d 2}{n(n^2-1)}$

n = 5, $n^2 = 25$, $\sum_d 2 = 2.5$

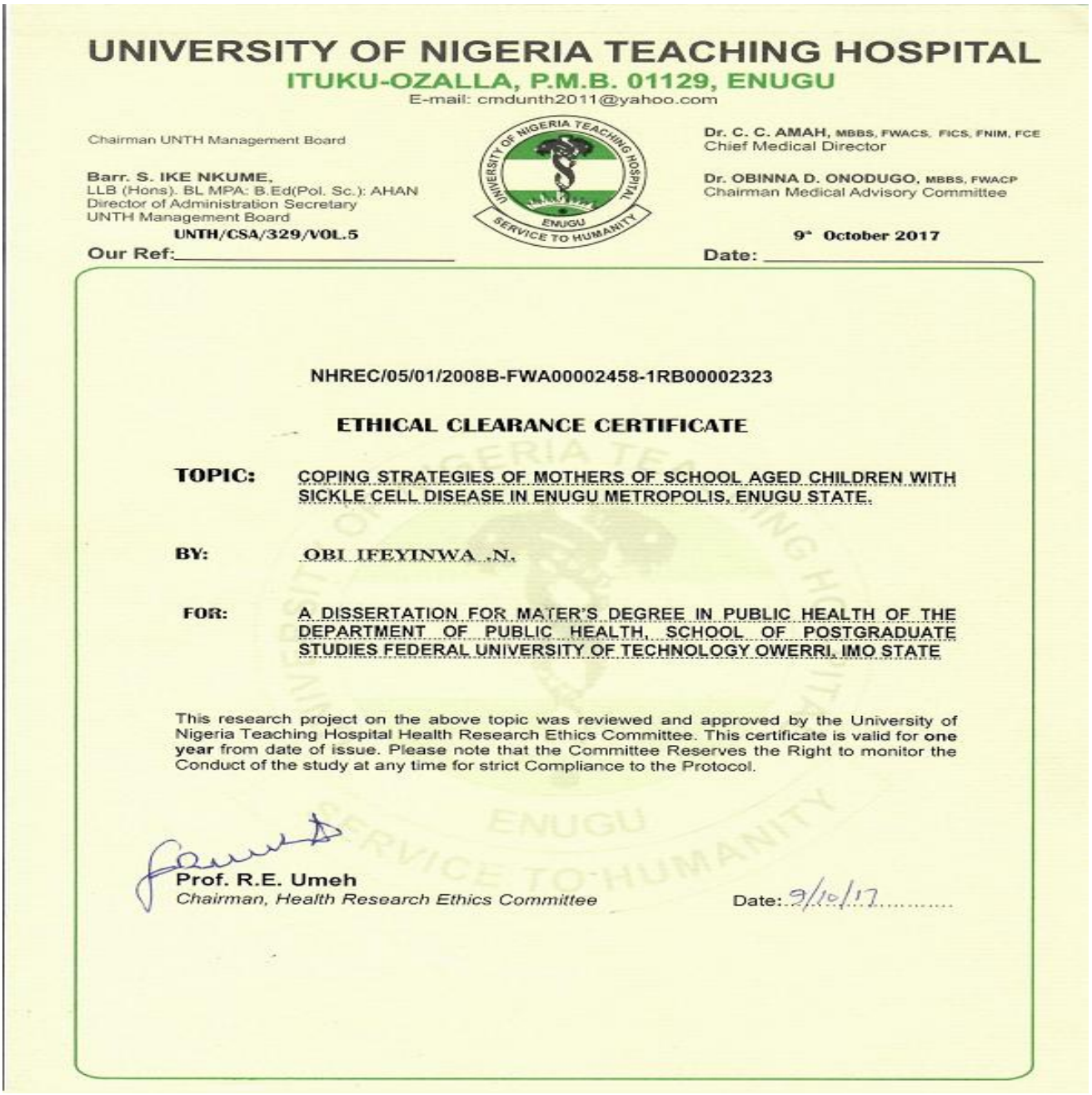
Putting these values in the formula above

$r_s = 1 - \frac{6\,(2.5)}{5(25-1)} = 0.875 \approx 0.88$

A co-relation of 0.88 was obtained.

APPENDIX D

ETHICAL CLEARANCE



UNIVERSITY OF NIGERIA TEACHING HOSPITAL

ITUKU-OZALLA, P.M.B. 01129, ENUGU

E-mail: cmdunth2011@yahoo.com

Chairman UNTH Management Board

Barr. S. IKE NKUME,
LLB (Hons). BL MPA: B.Ed(Pol. Sc.): AHAN
Director of Administration Secretary
UNTH Management Board

Dr. C. C. AMAH, MBBS, FWACS, FICS, FNIM, FCE
Chief Medical Director

Dr. OBINNA D. ONODUGO, MBBS, FWACP
Chairman Medical Advisory Committee

UNTH/CSA/329/VOL.5

Our Ref:_____

9th October 2017

Date: _____

NHREC/05/01/2008B-FWA00002458-1RB00002323

ETHICAL CLEARANCE CERTIFICATE

TOPIC: COPING STRATEGIES OF MOTHERS OF SCHOOL AGED CHILDREN WITH SICKLE CELL DISEASE IN ENUGU METROPOLIS, ENUGU STATE.

BY: OBI IFEYINWA .N.

FOR: A DISSERTATION FOR MATER'S DEGREE IN PUBLIC HEALTH OF THE DEPARTMENT OF PUBLIC HEALTH, SCHOOL OF POSTGRADUATE STUDIES FEDERAL UNIVERSITY OF TECHNOLOGY OWERRI, IMO STATE

This research project on the above topic was reviewed and approved by the University of Nigeria Teaching Hospital Health Research Ethics Committee. This certificate is valid for **one year** from date of issue. Please note that the Committee Reserves the Right to monitor the Conduct of the study at any time for strict Compliance to the Protocol.

Prof. R.E. Umeh
Chairman, Health Research Ethics Committee

Date: 9/10/17

APPENDIX E

INFORMED CONSENT

Department of Public Health Technology,
Faculty of Health Technology,
School of Post Graduate Studies,
Federal University of Technology,
Owerri, Imo State.
8th Jan, 2018.

Dear Respondent,

I am a post graduate student in the above mentioned Institution. I am carrying out a study on "**Coping strategies of mothers of school aged children with sickle cell disease in Enugu metropolis, Enugu state, Nigeria"** as part of requirement for graduation. Attached herewith is a questionnaire designed for gathering information for the study. Your response will be used only for academic purpose. The questionnaire has three sections A, B, and C. You are expected to answer all the items in all sections.

Thanks for your co-operation

Yours faithfully,

……
OBI, IFEYINWA.N.
(RESEARCHER)