University of Applied Sciences
Faculty of Life Sciences
Bachelor of Health Sciences

SICKLE CELL DISEASE AS A MAJOR PUBLIC HEALTH CONCERN IN NIGERIA

- Based on research and qualitative interviews -

- Bachelor thesis -

Presented by

Elele Ejodame

[redacted]

[redacted]

Submission date 26.02.2009

Supervised by

Prof. Dr. Dr. Karl-Heinz Wehkamp
Hamburg University of
Applied Sciences (HAW)

Prof. Dr. Gabrielle Perger
Hamburg University of
Applied Sciences (HAW)


5°E
10°E
NIGER
CHAD
SOKOTO
Sokoto
Katsina
KATSINA
JIGAWA
Kano
YOBE
BORNO
Lake Chad
Maiduguri
ZAMFARA
KANO
KEBBI
Zaria
KADUNA
Kaduna
BAUCHI
GOMBE
Kumo
BENIN
10°N
NIGER
Joa
NIGERIA
ADAMAWA
Yola
Niger
Abuja
PLATEAU
KWARA
ABUJA F.C.T.
Ilorin
OYO
Ogbomosho
Oyo
NASSARAWA
TARABA
Benue
Oshogbo
EKITI
OSUN
KOGI
Makurdi
Ibadan
BENUE
Abeokuta
Ondo
ONDO
OGUN
EDO
ENUGU
Benin City
Enugu
EBONY
LAGOS
Onitsha
ANAMBRA
Lagos
Sapele
CROSS-RIVERS
CAMEROON
DELTA
IMO
ABIA
5°N
Aba
Uyo
Calabar
Gulf of Guinea
RIVERS
BAYELSA
Port Harcourt
AKWAIBOM
0
100 miles
0
100 kilometres
5°E
10°E
©Oxford Cartographers

Table of contents

Acknowledgements

A very special thank you goes to all the people I interviewed in Nigeria for being so helpful, open and welcoming. Very many people contributed to this project by graciously spending the time to be interviewed and sharing their ideas with me. Without your valuable contributions and information, this project would not be.

I also covey my deep gratitude to the persons I interviewed who are affected with sickle cell disease. Thank you for sharing your experiences with me.

In particular, I would like to thank the coordinator of the Sickle Cell Foundation in Lagos for referring me to so many valuable contacts. I am especially grateful to Dr. Onaiwu who is the medical director of the Sickle Cell Centre in Benin City, Professor Akinyanju the chairman of the Sickle Cell Foundation in Lagos and Dr. Ihongbe who is the Head of Department of the College of Medicine at the Ambrose All University in Ekpoma. Thank you all for your energetic involvement and valuable input to this project.

I would also like to express my appreciation to my supervisors at the University, Professor. Dr. Dr. med. Karl- Heinz Wehkamp and Professor. Dr. Gabrielle Perger, thank you for your excellent supervision, guidance and friendly support through out this project.

I am especially grateful to my family. Thank you for your inspiration, support and encouragement in every way.

And lastly, I would like to thank God.

Thank you all for contributing to this project.

Figures and Tables

Figures:

Tables:

Abbreviations

CDC	Centre of Disease Control
Hb	Hemoglobin
HIV	Human Immunodeficiency Virus
Lab	Laboratory
IFAD	International Fund for Agricultural Development
NGO	Non Governmental organization
NAFDAC	National Agency for Food and Drug Administration and Control
NAPCA	National Action for Prevention and Control of AIDS
NPHCDA	National Primary Health Care Development Agency
NIMR	Nigerian Institute for Medical Research
NPI	National Programme on Immunization
SCD	Sickle Cell Disease
UNECA	United Nations Economic Commission for Arica
WHO	World Health Organization

Abstract

Background: In the year 2006, the WHO recognised Sickle cell disease to be a major public health concern in Nigeria. Due to the high population density, the prevalence rate of sickle cell disease in Nigeria is the highest in the world. Consequently, mortality rates are high and keep rising. Yet, sickle cell disease is not receiving the necessary attention required to address this major public health concern.

The aim of this project is to determine why sickle cell disease is regarded as a major public health concern in Nigeria. Furthermore, influencing factors affecting prevalence and mortality rates as well as efforts being made by the Nigerian government and Non Governmental Organizations (NGOs) to improve the situation will be analysed.

Method: Qualitative research was carried out in the year 2008 to investigate the present situation of sickle cell disease in the country. Through research and qualitative interviews carried out with 9 experts as key informants, the present situation was examined, analysed and evaluated. Data collection took place in different NGOs and governmental organizations over a 2 month period in different parts of Nigeria. Interviews were conducted with physicians, hematologists, genetic counsellors, sickle cell affected individuals, activists and medical laboratory scientists.

Results: Sickle cell disease can be properly managed resulting in a relatively normal and healthy life for the affected individuals. However, the disorder is responsible for very many unnecessary deaths in the country. This is caused by mismanagement of the disease due to ignorance, lack of awareness and lack of public education on the disease, socio-economic factors and inadequate health services in the country.

At the health service delivery level, research showed that there is only one publicly known government run sickle cell centre set up to manage the disease in the country. The majority of clinics and organizations advocating for sickle cell disease are non Governmental. There are only a few specialised clinics in the country.

Conclusion: A timely and energetic involvement by the Nigerian government is necessary to manage this growing public health problem in Nigeria. Partnerships and advocacies from NGOs are however necessary, and to some extent already exist, to assist the endeavours of the government. Influencing factors typical for Nigeria such as the socio economic situation, lack of public health education, need for health service improvements and so on should be taken into consideration when planning large scale intervention.

Introduction

According to the WHO, Nigeria has one of the highest prevalence rates of sickle cell disease in the world. It is a major public health issue for the country. To understand the present situation, it is necessary to find out what the available preventive measures are, what the consequences of this public health issue are for the country and to research what factors influence prevalence and mortality rates. To do this, organizations for sickle cell disease in different parts of Nigeria were visited and experts in this field of work were interviewed to get qualitative information.

Nigeria is the most populated country in Africa, with a population of 148 million (World Bank 2008a). Sickle cell disease has significant public health implications in the country. 24% of the population are carriers of the sickle cell gene[1] and it is estimated that every 2 out of 100 children are born with the disease. This means that in Nigeria alone, about 150 000 children are born annually with sickle cell disease. 50% to 80% of children born with the disorder will not reach the age of 5 years (WHO 2006a). Those that survive the first five years of age still remain at risk of premature death.

Sickle cell disease is responsible for immense death rates in the country, affecting the lives of many individuals and families directly and indirectly. It may have emotional, physical, mental, social or financial effects. Consequences like socio-economic effects, high morbidity and mortality rates can also be reflected on the country. High mortality rates are due to various reasons including on one hand the harsh effects of the disease itself on human beings and on the other hand mismanagement of the disease and ignorance due to lack of awareness and lack of public health education. Socio-economic factors and inadequate health care facilities and services also play a major role here.

If given the right attention, sickle cell disease could be converted from a killer disease to a chronic disease such as diabetes or hypertension for example; allowing those affected to live relatively normal and healthy lives. Unfortunately, sickle cell disease is not attracting enough efforts from the Nigerian government. This study endeavours to examine why this may be.

Other objectives of this study are:

- To examine the extent of involvement of the Nigerian health care system
- To identify problems and limitations of health workers in the fight against the disease
- To key out the consequences of the disease for the country.

Conclusively, this paper aims to find recommendations on how the situation can be improved on individual-, family-, community- and national levels

[1] healthy people who have inherited only one mutant gene from one parent, Hb AS

1. Sickle Cell Disease

This chapter gives information on the profile of sickle cell disease. It covers origin, hereditary factors, accompanying symptoms and effects, diagnosis, treatment possibilities and prognosis. It also highlights the management and prevention recommendations given by the WHO.

Sickle cell disease is a lifelong hereditary disorder of the blood. It is a hemoglobin disorder which results in anemia, occasional body pains and various infections in childhood. It could eventually result in organ damage.
Hemoglobin disorders are inherited blood diseases that affect oxygen transport in the body. They fall into two main categories which are **thalassaemia and sickle cell disease.** 300,000 people are born yearly with hemoglobin disorders, of these, 200,000 are born with sickle cell disease in Africa (WHO 2006a).

Thalassaemias are inherited blood disorders. People with thalassaemias are not able to produce enough hemoglobin, which is found in red blood cells and carries oxygen to all parts of the body. Without enough hemoglobin in the red blood cells, oxygen cannot be supplied to all parts of the body. Organs then become starved of oxygen and are unable to function properly. There are two major types of thalassaemias, alpha and beta, which are named after the two protein chains that make up normal hemoglobin. Alpha and beta thalassaemias have both mild and severe forms. In Africa, the prevalence of thalassaemia among blacks is 0.9%. It is more common in some European countries like Italy or in Cyprus where it is up to 16%, and in Asian countries like Thailand, China, India etc. (National heart lung and blood Institute 2008a).

1.1 What is Sickle cell disease?

Sickle cell disease is a genetic condition in which red blood cells contain an abnormal form of the oxygen-carrying protein hemoglobin. This abnormal form is called Hb S and the normal hemoglobin form is AA. Hence, children who inherit sickle cell genes from both parents will develop sickle cell disease with the trait SS, while those who inherit the gene from only one parent will have the sickle cell trait AS. Those with the AS trait have no symptoms but can pass the gene on to their offspring. Apart from hemoglobin S, there are other types of abnormal hemoglobin such as alpha and beta thalassaemias, hemoglobin C, hemoglobin D, haemoglobin E. There are also a few other rare forms like Hb O-Arab form (Department of health and senior services Missouri 2008). Sickle cell is common in sub-Saharan Africa, Saudi Arabia, India, Mediterranean countries (WHO 2006a).

Hb S is the most common of these hemoglobins in the world and in Africa. The second most common variant hemoglobin in Africa is Hb C. The Hb C originated from Northern Ghana and Burkina Faso, where about 1 in 5 (20%) of the population are carriers of the HB C trait. The Hb C is also found in western Nigeria and among the black populations of America, Europe and the Caribbean. The Hb S and Hb C forms can co-exist together. If a person inherits the Hb S trait from one parent and the Hb C trait from the other parent, he can have Hb SC. This form exists but the symptoms are less severe and less frequent than those of a person with Hb SS (Sickle Cell Foundation Nigeria 2008a).
Since the Hb S form is the most common in Nigeria and has the most severe consequences, the focus on this paper will therefore be on this form, Hb S.

Figure 1

The following illustration shows the abnormal form of a sickle cell and the normal red blood cell. (Natural Sciences Learning Centre 2003)

The hemoglobin S makes the red blood cells become hard, sticky and take on a different shape from the normal round or oval shape. They become sickle shaped making them fragile and easily destroyed. This makes it difficult for these abnormally shaped cells to go through small vessels, thus causing blockage and depriving body organs of blood and oxygen. This results in a chronic slow deterioration of multiple organ systems culminating in recurrent episodes of severe pain, anemia, serious infections and damage to vital organs. Further complications could include stroke, kidney damage, damage to the central nervous system, respiratory problems among others (Sickle cell disease association of America Inc. 2008).
The term *sickle cell disease* is therefore preferred, because it is more comprehensive than *sickle cell anemia,* covering more disorders than anemia alone (WHO 2006b).

1.1.1 The history and origin and its connection to malaria

Most of the earliest published reports of sickle cell disease were of black patients living in U.S.A. In 1846 one of the first descriptions of sickle cell disease took place. The case of "Absence of the spleen" was diagnosed in a black male body that was autopsied by Lebby. R. This was documented in the southern journal of medical pharmacology.

The next documentation was in 1904, when a Dr. James Herrick and his intern Dr. Ernest Irons reported some “peculiar elongated and sickle shaped red blood cells” in a 20 year old black person. The patient had called on Dr. Herrick with complaints about symptoms like shortness of breath, heart palpitations, abdominal and muscle pains, tiredness, headaches, leg ulcers etc. (Gladwin, American Society of Haematology 2008).

In the 1940s, E.A. Beet, a British medical officer stationed in Northern Rhodesia (now Zimbabwe) held a theory as to why sickle cell disease was common in the tropical regions. This was its association with malaria. He observed that blood from malaria patients who had sickle cell trait had fewer malaria parasites than blood from patients without the trait. In 1954, Anthony Allison from the California institute of technology, continued to build on these observations and made a hypothesis that sickle cell trait offered protection against malaria. His theory was that those with the trait did not get malaria as often as those without it; but when they did, their disease was less severe (African traditional herbal research clinic 2008).

It is now known that when malaria parasites enter the blood stream, the oxygen levels reduce, presumably because the parasite reduces the oxygen tension within the red blood cells to very low levels as it carries out its metabolism. Normally, stable red blood cells of a person with the sickle cell trait only sickle in a low oxygen environment. If the malaria parasite attacks healthy red blood cells, they sickle under the low oxygen levels, destroying these cells. This reduces the amount of malaria infected cells in the bloodstream. This process allows the person survive more acute malarial infections. However, those with the Hb AA or Hb SS do not have this advantage over malaria (Sickle cell information centre Georgia 2004a). Therefore, in regions with high malaria transmission, people who carry the sickle cell trait, e.g. Hb AS will have a greater chance for survival.

Sickle cell disease was known in Africa before the twentieth century. African literature shows that different tribes were conversant with sickle cell disease and used various names for it. In different tribes in Ghana for example, the people had names for it, each of these names have repeating syllables, as if to symbolize the repeating painful episodes.
Such names include *ahututuo* from the Twi tribe, which means “Aoo, I’m dying”; *chwecheechwe* from the Ga tribe, which means “relentless, perpetual chewing”; *nuidudui*

from the Ewe tribe meaning “body chewing”; and *nwiiwii* from the Fante tribe which means “I will die eeh”. Many of these tribal names were imitations of the cries and moans of the sufferers. The Banyangi tribe of Cameroon called it *Adep* meaning “beaten up”. In Nigeria, sickle cell disease was associated with reincarnation; children who come and go. In the Igbo tribe in Nigeria, they were known as “Ogbanje”. These children mostly died at infancy. From the many children born into a family, there were likely to be more than one child with sickle cell disease. Thus, these people believed that their children were reincarnated and came back to join the family. They believed that an evil spirit was trying to be born into their family through the Ogbanje children, but the babies bravely died to save the rest of the family. In the Yoruba tribe of Nigeria, these children were known as “Abiku” (Ballas 1994, p. 3-5).

1.1.2 How sickle cell disease is transmitted

Sickle cell disease is inherited as an autosomal recessive trait. This means it occurs in someone who has inherited the Hb S gene from both parents. If a person inherits hemoglobin S from one parent and normal hemoglobin A from the other parent, he or she will have the sickle cell trait. A person who inherits hemoglobin S from one parent and another type of abnormal hemoglobin from the other parent will have another form of sickle cell disease, such as thalassaemias or Hb SC. (Sickle Cell Society London 2004)
The following diagrams show how sickle cell disease or the trait of sickle cell disease can be transmitted from parents to offspring.

Figure 2

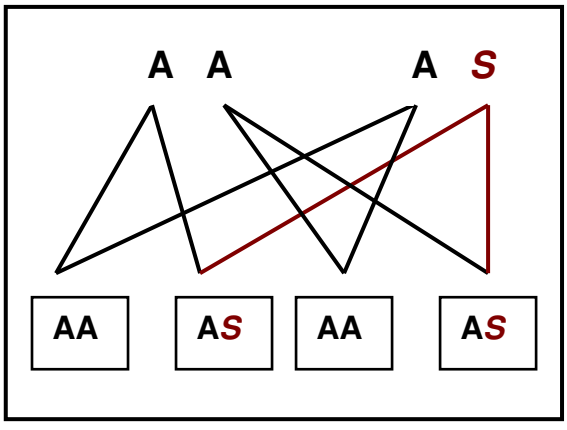


Figure 2 illustrates the combination of two individuals, one with the usual hemoglobin AA and the other with the sickle cell trait hemoglobin AS.

None of the children will get sickle cell disease but there is a one in two (50%) chance that any given child will get one copy of the Hb S gene and thus inherit the sickle cell trait. In the

same way, it is equally likely that any given child will get two Hb A genes and be completely unaffected.

Figure 3

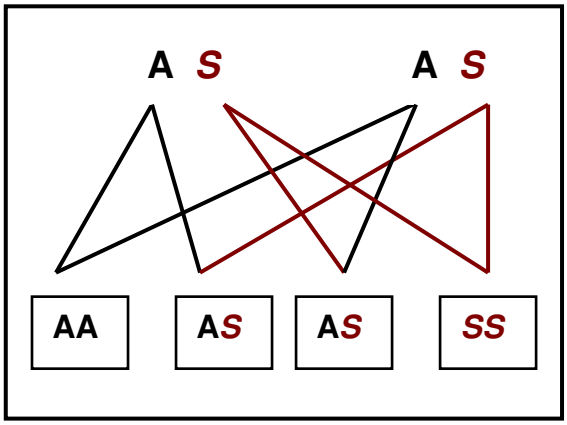


Figure 3 illustrates the combination of two individuals with the sickle cell trait, hemoglobin AS coming together to have children. Both parents have the sickle cell trait Hb AS. There is a one in four (25%) chance that any child could be born with sickle cell disease. There is also a one in four chance that any child could be completely unaffected and there is a one in two (50%) chance that any child will inherit the sickle cell trait.

Figure 4

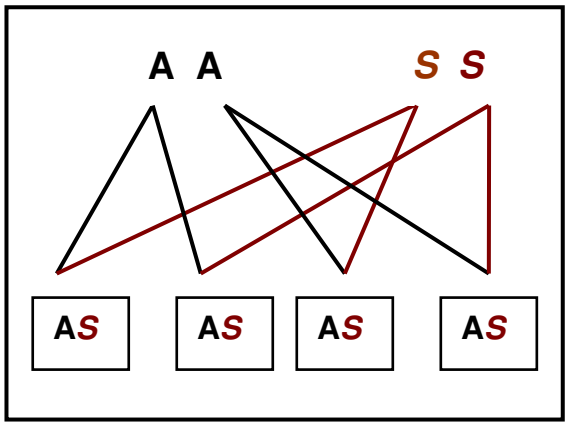


Figure 4 illustrates the combination of two individuals, one with the unusual Hb SS and one with the normal HB AA.

One parent has sickle cell disease, Hb SS and the other is completely unaffected Hb AA. All the children will inherit the sickle cell trait and none will have sickle cell disease.

1.1.3 Symptoms and Complications

The symptoms of sickle cell disease do not usually occur until the first 4 months of life. Pale skin or yellow eyes may be first noticed due to anemia. The yellow eyes are known as jaundice. Other symptoms are bone pains, abdominal pains or swelling. Swelling and pain of the hands and feet are common in young children. Some may get fever, chest infections and have rapid breathing.

Blocked blood vessels and damaged organs can cause acute painful episodes known as "crisis". There are several types of crisis:

- Hemolytic crisis: This occurs when damaged red blood cells break down rapidly. The body cannot produce red blood cells fast enough to replace those being destroyed.
- Splenic sequestration crisis: Occurs when the spleen enlarges and traps the blood cells.
- Aplastic crisis: Results when an infection causes the bone marrow to stop producing red blood cells.

(University of Maryland medical centre 2008)

These painful crises occur in most sickle cell affected at some point in their lives. A crisis could last from hours to days, affecting the bones of the back, the long bones, and the chest. Some patients have a crisis every few years, while others have many episodes per year. It depends on the individual and influencing factors. The crises can be severe enough to require admission to the hospital for pain control, blood transfusion and intravenous fluids[2].

Repeated crisis can cause damage to vital body organs. Blocked blood vessels may cause strokes that damage the nervous systems. In older people, lung and kidney functions may deteriorate. The liver may become larger through life and gallstones may occur. The spleen may also become progressively larger with time and stop functioning properly. Because the spleen helps fight body infections, many affected may suffer viral-, bacterial- and lung infections (National heart lung and blood institute 2008b). Other symptoms include joint pains and fever, due to changes in the bone marrow. The hip joint may become damaged or dislocated and need replacement. Breathlessness, delayed growth and puberty, delayed menstruation in young girls, fatigue, enlargement of the heart and rapid heart rates, susceptibility to infections and ulcers on the lower legs in adolescents and adults are not uncommon. The patient may also have hematuria[3], excessive thirst, frequent urination and

[2] Also known as IV and Intravenous drip, it is the giving of liquid substances directly into a vein
[3] Urine containing blood or blood stained urine

painful erection known as priapism. This occurs in 10% - 40% of men with the disease. The frequent occurrence of priapism may permanently damage the penis (National heart lung and blood institute 2008b).

The sickle cell trait usually does not cause any problems. There are a few cases of 1% to 4% of people who get painless hematuria. Rarely, people die suddenly while undergoing very strenuous exercise that causes severe dehydration, such as during military or athletic training (Sickle cell information centre Georgia 2004b).

1.1.4 Diagnosis

Sickle cell can be diagnosed through a blood test. Sickle shaped red blood cells and fragments of destroyed red blood cells can be seen in a blood sample through a microscope. If the test shows some sickle shaped hemoglobin, a second blood test is usually carried out to confirm the diagnosis. Early diagnosis of sickle cell disease is important to give children timely and proper treatment. It is also possible to diagnose sickle cell disease before birth. This is through a prenatal diagnosis. This is done using a sample of amniotic fluid [4] or tissue taken from the placenta. This test can be done as from 14 weeks into the pregnancy (National heart lung and blood institute 2008b).

1.1.5 Treatment

Patients with sickle cell disease need continuous treatment. Medical supplementation with folic acid, an essential element in producing red blood cells, is required because of the rapid red blood cell turnover. The purpose of treatment is to manage and control symptoms, and to try to limit the frequency of crisis. In malaria endemic areas, anti malaria drugs are also frequently taken to prevent malaria.

During a sickle cell crisis, certain treatments may be necessary to manage pain. This could include analgesics[5], enough liquid intake and sometimes blood transfusion. To treat pain, non-narcotic medications may be effective, but some patients require narcotics. Frequently however, the pain is incompletely treated. This is because of the fear of physical and psychological dependence, side effects and intolerance when administering narcotic analgesics (Ballas 1994, p 146 -254).

Hydroxyurea (Hydrea) is a drug used for some sickle cell disease patients to reduce the number of episodes of pain including chest pain and difficult breathing. Antibiotics and

[4] Amniotic fluid is the fluid in the sac surrounding a growing embryo
[5] Adverse group of drugs used to relieve pain

vaccines are given to prevent bacterial infections, which are common in children with sickle cell disease. If addictions occur from analgesics used for painful crises, drug rehabilitation may be necessary. If there are significant gallstones, gallbladder removal may become necessary. Among others, treatments include hip replacement for avascular necrosis[6] of the hip, irrigation or surgery of the penis due to priapism, surgery for eye problems, transfusions or surgery for brain problems, such as strokes and wound care like zinc oxide, or surgery for leg ulcers. Counselling for the psychological complications of having sickle cell disease may also be necessary (National heart lung and blood institute 2008b).

Bone marrow transplants can cure sickle cell disease. However, only a few people with this disease are compatible for the transplant. This is because only a few are able to find a suitable donor. Bone marrow transplantation may also include risks, including infection and rejection. According to the sickle cell information centre in Georgia, USA, about 200 children worldwide have been completely cured of sickle cell disease in the last 20 years through bone marrow transplant. However, to get a bone marrow transplant, there are certain criteria a patient must fulfill. He or she must be under the age of 16 as the risk of failure of the transplant increases with age. The patient must furthermore have severe symptoms but no long term organ damage. About 10% of those who have a bone marrow transplant die from the complications following the procedure. Only about 7% of those affected meet the criteria for the transplant. A bone marrow transplant costs between 150 000 and 250 000 U.S. dollars (Sickle cell information centre Georgia 2008).

Those who are not compatible for a bone marrow transplant can however improve their quality of life if they adhere to their limitations and the dos and don'ts of the sickle cell disease. There are general ways of reducing the number of sickle cell crises which may occur. This is by maintaining a clean environment with good personal hygiene to prevent mosquito breeding. In Malaria infected areas, sickle cell affected should be protected from mosquito bites, malaria preventive drugs should be taken as prescribed. Protection from infections and exposure to cold weather and rainfall should be exercised. Strenuous physical activities should be avoided. Smoking and alcohol consumption should be prevented as this is potentially damaging. There should be high fluid intake and the doctor's prescriptions and advice should be followed. Good nutrition is also a very important factor in the lives of sickle cell affected individuals (Sickle Cell Foundation Nigeria 2008a).

[6] Death of the hip joint

1.1.6 Prognosis

In the past, death from organ failure often occurred between the ages of 20 and 40 years in most sickle cell patients. More recently, because of better understanding and management of the disease, many patients live into their forties and fifties. The prognosis for any individual depends on different factors. But if a patient receives proper medical care and is adherent to the individual limitations, he or she may learn to lead a relatively normal life with the disorder.
In the United States of America median survival was estimated in 1994 to be 42 years for men and 48 years for women. Comparable figures for Jamaica published in 2001 suggested 53 years for men and 58.5 years for women (WHO 2006).
There is no concrete data on the survival of patients with sickle cell disease in Africa. In Nigeria however, more than 50% of children affected with sickle cell disease die under the age of 5 years (WHO 2006b).
Research during this paper however showed that there are a number of people who have lived well over 50 years of age, some reaching over 70 years and are still alive (Interview with the Sickle Cell Foundation Nigeria 2008).

1.2 Management and Prevention of Sickle cell disease

Sickle cell disease is a genetic disorder which has no prevention other than genetic screening. Couples can have tests before getting married to find out if they carry the gene for sickle cell anemia. If they find out that they are both carriers they can decide whether or not to have children. If they decide to go ahead and have children, they would be aware of possible consequences.

Another preventive measure is the prenatal diagnosis. If a woman is pregnant and finds out in the early stages that her unborn child will have sickle cell disease, she can either decide to have the child and give it proper treatment from the beginning or she may decide to terminate the pregnancy. This has an ethical aspect which differs from culture to culture and is also hindered by the fact that abortions are illegal in some countries. In Nigeria for example, a prenatal Diagnosis costs 400,000 Naira, the approximate value of 3,000 U.S. dollars which is not affordable for most people (Interview with the Sickle Cell Foundation Nigeria 2008).

Additionally, the neonatal screening is a way of early diagnosis of sickle cell disease in infants. This could ensure that early treatment and care is given to these children allowing them better prospects and chances of living healthy, normal lives. Unfortunately, neonatal screening for genotypes is not a standard measure in most developing countries. This means

that children born with sickle cell disease may not be diagnosed until symptoms start to set in and become noticed.

1.2.1 WHO recommendations on management and prevention strategies

In the report of the fifty ninth world health assembly of April 2006, the World Health Organisation recognised sickle cell disease as a major public health concern in many African countries. The report gave recommendations on the prevention and management of sickle cell disease. It stated that genotype screening and prenatal diagnosis are important factors when planning intervention that must be accompanied with health education. The report said experience showed that genetic counselling linked with the offer of prenatal diagnosis can lead to a large reduction in births of affected children. To carry out such screening programmes, a training programme for health care workers or other professionals will be required. This would be by way of a carrier screening programme. The WHO advices that these measures be practiced in compliance with three essential principles of medical genetics: the autonomy of the individual or the couple; their right to adequate and complete information; and the highest standard of confidentiality.

It also stated the importance of neonatal diagnosis, which may only be useful when accompanied by adequate and efficient primary health care and appropriate counselling for the parents.

Furthermore, the report stated that sickle cell disease has economic consequences for the countries affected. The provision of diagnosis and treatment will lead to an increase of those needing care which leads to an increase in annual cost per patient. These can have vast implications on countries with limited resources. The urgent need for a comprehensive approach to prevention and management of sickle cell disease was mentioned. Surveillance and education must be delivered at the community level through the primary health care system so as to increase public awareness of the problem and lengthen the survival of affected individuals.

The WHO stated that the most important aspect for a better management is to improve the prospects of those living with sickle cell disease in developing countries. This can be done by early intervention. Intervention for preventable problems can be done with the use of pain medication, antibiotics, nutrition, folic acid supplementation, high fluid intake and treatment with hydroxyurea. It also stated the importance of prenatal and neonatal diagnosis accompanied with health education and counselling.

The report commended accomplishments like the long term treatment of the disease with hydroxyurea, the availability of regular blood transfusions, bone marrow transplants, availability of prompt management of stroke and other resulting organ damage. All these

have increased quality of life of those affected with sickle cell disease. The WHO however sees these approaches predominantly in high resource countries. This thus widens the gap in terms of quality of life between patients in developed countries and those in developing countries. This gap can be reduced only through a general improvement in health services in these countries (WHO 2006a).

2. Epidemiology of Sickle Cell Disease

This chapter gives information on statistics about prevalence-, incidence- and mortality rates of sickle cell disease in different parts of the world.

2.1 Epidemiology world wide

Sickle cell disease is particularly common among people whose ancestors come from sub-Saharan Africa, India, and Saudi Arabia and Mediterranean countries. Sickle cell disease is also common in African Americans. This is due to migration. Prevalence rates in other countries like in Europe for example are slowly increasing due to migration (WHO 2006a).

In the United States about 70,000 African Americans have sickle cell disease which is about 1 in 400 African Americans. 2 million people have the sickle cell trait (CDC 2008).

In the United Kingdom 600,000 babies are born yearly about 250 babies of these are born with sickle cell disease (UK new born screening programme 2005).

In year 2006 in Germany it was estimated that about 1000 people were living with sickle cell disease in the country. Most of them were immigrants from the Middle East, Africa and Asia (Dickerhoff 2008).

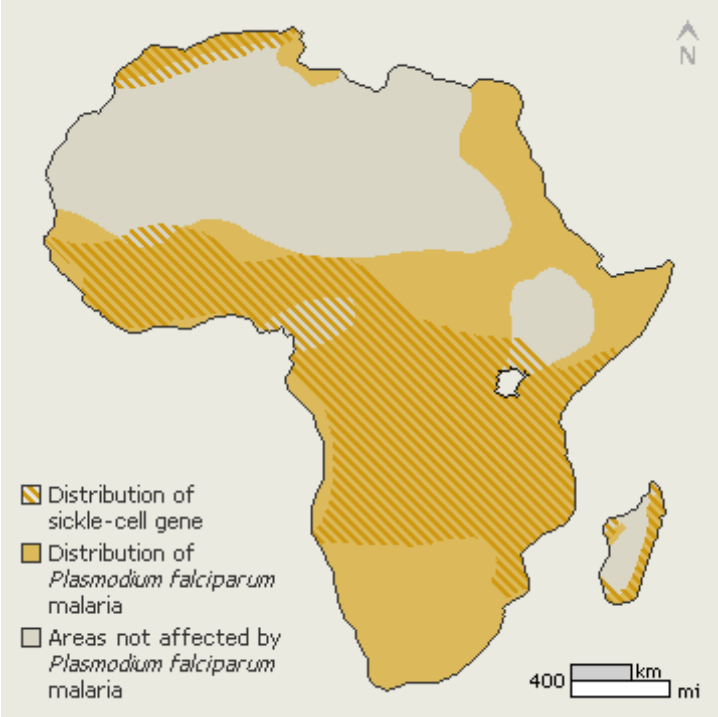
2.2 Epidemiology in Africa

About 70% of all sickle cell disease affected people world wide are in Africa, estimated at over 12 million. The prevalence of sickle cell disease is estimated at over 2%. Infant mortality is about 8% and survival rate of affected babies in rural areas by five years of age is about 20% (UNECA 2008).

The prevalence of the sickle cell trait ranges between 10% and 40% across equatorial Africa and decreases to between 1% and 2% on the North African coast and is less than 1% in South Africa. This distribution emphasises the connection between malaria endemic areas and the prevalence of the disease. In West African countries such as Ghana, Nigeria and Cameroon, the frequency of the trait is 15% to 30% whereas in Uganda in some tribes it reaches 45% (WHO 2006a).

Figure 5

This figure shows the geographic distribution of the sickle cell trait and malaria in Africa (MSN Encarta 2008).



2.3 Epidemiology in Nigeria

Nigeria, officially "The Federal Republic of Nigeria" is located in West Africa, on the Gulf of Guinea. Nigeria has a total area of 923,768 km²; of that around 13,000 km² is water. Nigeria has a 4,047 km border it shares with Benin, Cameroon, Chad and Niger.

Nigeria's population is estimated to about 148 million. It is the most populated country in Africa. The population makes up about 47% of West Africa's population. The country has 36 states and over 200 different ethnic groups and 500 indigenous languages. Abuja is the federal capital of Nigeria. There are three main ethnic groups in Nigeria: The Yoruba tribe in southwest Nigeria, the Igbo tribe in southeast Nigeria and the Hausa-Fulani in northern Nigeria (World Bank 2008).

According to World Health Organization statistics, 4 million Nigerians have been estimated to have sickle cell disease and 25 million to be carriers of the trait In Nigeria. 150,000 children are born yearly with sickle cell disease. Each year, over 200,000 babies are born with sickle cell disease in Africa, 60% of those will die in Nigeria. Nigeria accounts for almost 80% of infant death cases from sickle cell disease in Africa (WHO 2006a).

3. The Nigerian Health System and existing sickle cell organizations

This chapter gives information about existing organizations and health services in Nigeria for sickle cell disease. The first part focuses on the Nigerian health system and existing organizations run by the government while the second part covers Non Governmental organizations.

3.1 The Nigerian Health System

The Nigerian Health system is run by three different government levels in the country with private health care providers playing a major role as well. The federal government is responsible for the tertiary health institutions such as the university teaching hospitals and federal medical centres. The state government manages secondary health institutions which are the various general hospitals and comprehensive health centres. The local government focuses on dispensaries and primary health services. Apart from these, there are many clinics and hospitals privately run across Nigeria.

The tertiary health institutions include the university teaching hospitals which are responsible for medical schools and the training of doctors. The secondary health institutions are responsible for training nurses, midwives and health extension workers, while the primary health institutions provide basic health services and manage the primary health care facilities.

Certain arrangement constraints arise through the fact that Nigeria functions under a federal government. The federal ministry of health for example cannot enforce the implementation of any health policies and programmes to the state ministry of health. This may make legislation and health policy implementation difficult on a national level.

The health system is split into different divisions that are responsible for different areas of health. These include NAFDAC (National agency for food and drug administration and control), NPHCDA (National primary health care development agency), NAPCA (National action for prevention and control of AIDS), NPI (National programme on Immunization) and NIMR (Nigerian institute for medical research).

The financing of the health care system in Nigeria comes from the budget allocations of the three government levels as well as from private sponsorship, loans and grants.

The Nigerian health sector is also supported by international organizations like the WHO, World Bank, United Nations etc. The WHO for example has over 23 areas of work in Nigeria, including disease prevention, health systems and community health, health technology and so on. Projects are HIV, malaria, immunization, surveillance, child and adolescent health, food safety and many others (WHO Country cooperation strategy Nigeria 2005).

The number of physicians, per 1000 people was estimated to be only 0.3 in year 2003. The health expenditure in Nigeria in 2005 was about 3.9% of GDP[7] (IFAD 2008).
In one of the "Health for All" global strategies, the WHO advised that member states spend a minimum of 5% of the countries GDP on the health sector.
In the world health report of 2000, the WHO stated that the performance of the Nigerian Health system is worse than many sub-Saharan countries. The report highlighted the urgent need to support the health system with adequately trained personnel to improve the health services (WHO 2000).

The Nigerian health system is challenged by many factors in the country. These include the high population density in the country, the socio-economic situation (Statistics show that in year 2007 about 54% of Nigerians were living below the poverty level which is 1 US dollar per day, World Bank 2008) which has led to wide spread poverty, illiteracy levels, urbanization and related rural-urban migration, the presence of many communicable and non communicable diseases, and corruption are among many present factors the health sector is confronted with.

3.2 Governmental Organizations for sickle cell disease

The only known sickle cell centre run by the government is in Benin City of Edo state, west of Nigeria. Apart from this centre, there are a few hematology clinics in some tertiary institutions which can give specialized care to sickle cell patients. Aside these, most of the sickle cell clinics and centre's are Non Governmental Organizations.
The Sickle Cell Centre in Benin was commissioned in 1993. It started as a project set up by a wife of a state governor who had personal interest in sickle cell disease. The centre was later taken over and developed by the federal government.
The centre has different services. It functions as an information- and counselling centre for sickle cell affected and their families. Patients can get their medication at this centre. It offers a telephone help line. Those affected or their families can call and get counselling or advice on what to do in their situation. It serves as good means of reaching out to people and a good disease management measure.
Sickle cell disease affected individuals can visit the centre in Benin to get an attestation stating that their sickle cell status will not affect their jobs in any way. This option is for affected who may be discriminated when applying for jobs because of their sickle cell disease status. The centre also occasionally organizes educative programmes to reach out to the public.

[7] Gross Domestic Product

3.3 Non Governmental Organizations for sickle cell disease

The Research and qualitative interviews have shown that apart from the Sickle Cell Centre in Benin City, it is the Non Governmental Organizations that play a vital role for sickle cell disease in Nigeria. There are a number of NGOs such as sickle cell foundations, centres, clubs and clinics situated around Nigeria.
Lagos state, located in the west of Nigeria with an estimated population of about 17 million people (Lagos state government 2006), has the most NGOs for sickle cell disease in the country. There is a National Sickle Cell Foundation in Lagos state. It is the largest organization of this kind and it coordinates various programmes and projects. The foundation trains health workers from different practices and institutions nationwide on genetic counselling. It offers genetic counselling to affected individuals or carriers of the sickle cell trait. The foundation works in co-operation with other clinics, to which it refers patients for treatment, prenatal diagnosis and so on. The foundation supplies other centres with free drugs and also offers free drugs to patients. It organises educative and awareness programmes for health workers and the general public. It functions as a central body, where other NGOs can register and become accredited.
The foundation being an NGO is dependent on sponsoring and donations. An interview with one of the members of the foundation showed that funding has been a challenge. To mention a few, laboratory facilities and equipment are required and more staff needed.

This foundation has a partnership with a mobile telecommunications company in Nigeria (MTN Foundation). The MTN Foundation sponsors the Sickle Cell Foundation to help set up sickle cell clinics for the provision of preventive and curative health care services. The MTN Foundation also sponsors the Sickle Cell Centre in Benin City.
Apart from this Sickle Cell Foundation, there are seven sickle cell clubs and a few specialised clinics in Lagos state. The functions of sickle cell clubs are to carry out public education and to inform the public about the disorder and increase tolerance among family members, friends and employers. They offer counselling about the genetic, medical and social aspects of the disorder to families, relatives and the general public.

There are also a number of smaller NGOs in the state. For example one NGO is run by a woman who has sickle cell disease herself and is an activist. She offers counselling services to people affected who want to talk and share their experiences. There are a number of NGOs in other states as well. In the North of Nigeria in Katsina state, there is the “Sickle Cell Health Patient Information Centre”. In Bayelsa state in the Niger Delta region south of Nigeria, there is the “Sickle Cell Health Watch”. In the east of Nigeria in Imo state, there is

the “Cardan Centre”, which is a subsidiary of the foundation in Lagos state. In Ibadan, Oyo state, West Nigeria, there is the “Elewura Sickle Cell Centre”. This is also a subsidiary of the foundation in Lagos state. Apart from these, there are a few other NGOs, clinics and clubs in Nigeria. None of these however have the magnitude of the Sickle Cell Foundation in Lagos state.

There are still many rural and urban areas in Nigeria, where sickle cell disease has received little or no attention. For example a commercial city like Port Harcourt which is the centre of Nigeria’s oil industry in Rivers state has a high mortality rate from sickle cell disease. Port Harcourt has a lot of rivers around it which support mosquito breeding. Those with sickle cell disease in these areas are endangered by the high rate of malaria. Port Harcourt does not have any known sickle cell centre. It however has a university teaching hospital where some studies concerning sickle cell disease are sometimes conducted. More facilities may however be necessary to support more research.

The Nigerian sickle cell expert advisory committee

A private committee was initiated about a year ago involving experts and interested individuals from different parts of Nigeria. The committee is a representing body set up to advice the government on matters concerning sickle cell disease and to share experiences from the different areas and regions in the country. The aim of the committee is to get the government more involved in the fight against sickle cell disease in Nigeria. One of the experts interviewed, stated that the challenges of setting up this committee, have so far been funding.

Setting up meetings, involves transportation and accommodation of various members from the different parts of the country. This alone poses a problem. A lot therefore depends on funding. The sooner the committee is put into action, the sooner the attention of the government is gotten and hence the faster advocacies and changes can take place.

In summary, the research showed that there are some organizations for sickle cell disease but with limited means and much too few. The services offered by many of these organizations are therefore limited and mostly small scale. A large scale intervention is necessary and strongly dependent on funding. Much therefore depends on the government involvement and budget and perhaps to some degree on the success of the Nigerian sickle cell expert advisory committee.

4. The Qualitative Interviews

This chapter is about the design and methods used to carry out research. It is about the choice of interview type, data collection methods and tools used to analyse the researched and collected data. This chapter also includes limitations faced with while conducting research.

4.1 Goals and aims of the interviews

This research was carried out to examine the present situation of sickle cell disease affected in Nigeria and the extent of involvement of the health care system, government and NGOs, in the fight against the disease. Knowing that Nigeria has the highest prevalence rate of sickle cell disease in the world, the aim was to investigate why this may be so and what present efforts are being made to reduce the mortality and morbidity rates caused by sickle cell disease in the country.

4.2 Methodology

4.2.1 Preparation

(Creation of questionnaire, choice of qualitative interviews)

To examine and evaluate the situation, qualitative interviews were carried out with experts from different fields of sickle cell disease. The choice and goal of the qualitative interview was to create an interview design in which the questionnaire would allow for a description of the present situation, examine the needs, problems and challenges of those involved in the fight against sickle cell disease and give opportunity for improvement - suggestions and recommendations.
A questionnaire with open end questions was created, allowing the persons interviewed have the freedom to give their answers and not have to choose from limited options. This was done to ensure that qualitative, non-biased information is given. The questionnaire consisted of 12 main questions with varying sub questions depending on which expert was interviewed.

4.2.2 Data collection

The data collection was carried out during a 2 month period between November 2008 and January 2009 in Nigeria. The researcher contacted a member of the Sickle Cell Foundation in Lagos state via email about 2 months before arrival and asked for the opportunity to visit the foundation and carry out some interviews. Through the Sickle Cell Foundation in Lagos,

other contacts were established. Apart from Lagos state, research was carried out in Edo state at the government run Sickle Cell Centre in Benin City and at the College of Medicine at the Ambrose Alli University of Ekpoma also in Edo state.
The target was to interview a minimum of 7 experts. On the whole, 9 complete interviews were carried out and a few additional shorter discussions with other interviewees.

Table 1

This table gives an overview of the 9 experts interviewed in Nigeria.

Profession / Expertise	Age in years	Relevance
1. A Health management and information science student. Working parallel in an NGO.	20 - 30	The interviewee has sickle cell disorder and has been an activist for about 4 years.
2. A Medical doctor at an NGO	31 - 40	This person works in different sickle cell clinics.
3. Medical lab. scientist, haematologist and genetic counsellor.	51 - 60	The interviewee has been in this field of work for over 25 years
4. The executive director of an NGO.	41 - 50	This interviewee has managed this NGO for 1.5 years and has sickle cell disorder.
5. A Medical doctor in a governmental organisation	51 - 60	A physician specialised in Internal medicine. The person has sickle cell disorder and has been in this field of work for 26 years.
6. A haematologist and genetic counsellor	41 - 50	This person has been working in this field for over 18 years and teaches genetic counselling.
7. A medical lab. scientist	51 - 60	This person has been working in this field for over 30 years and is a carrier of the sickle cell trait.
8. The director of an NGO. A haematologist and genetic counsellor.	70 - 80	This interviewee has been in this field of work for over 38 years.
9. A banker.	20 - 30	This person was interviewed to get a neutral opinion and view on this matter.

The goal was to interview experts such as hematologists, sickle cell affected individuals, genetic counsellors, professors and health workers directly involved with sickle cell disease. A random person not directly affected with sickle cell disease was to be interviewed as well. This was to get a neutral opinion from a “non expert”. These experts were chosen as key informants whose field of work or personal experience give them enough exposure to the topic to be able to give valuable and qualitative information, also enabling then to estimate the situation of sickle cell disease in the country efficiently.
Apart from these interviews, other shorter discussions were held with a hematologist, a person who is a carrier of the sickle cell trait, a pharmacy student and a young man who lost his brother to sickle cell disease.
All the expert interviews took place face to face. 4 women and 5 men were interviewed. Each interview lasted about 40 minutes to one hour. The researcher did not use any voice recording measures but wrote down the information directly during the interviews.

4.2.3 Data Analysis

(Building of categories)

Data analysis and evaluation were carried out via category building. The answers were classified into 6 different categories according to the questions. This was done to emphasize similar patterns in the answers of the different interviews and bring the information gathered into a logical qualitative form.

The categories are as follows:

- Sickle cell disease in Nigeria, influencing factors and consequences
- Health services and organizations for Sickle cell disease
- Public health and intervention
- The individual and external factors
- Future prospects
- Others

See Annex for the categories and questionnaire.

4.3 Limitations

This research covers information gathered from health service centres for sickle cell disease in only the western and southern parts of the country. These areas were strategically chosen to cover the governmental organization in the south and the most important and far reaching

NGOs in Lagos state in the west. A nation-wide research would not have been possible within the scope of this study.

However, since there are only a few smaller centres around the nation, and the sickle cell centre in the east in Imo state is a 2 month old subsidiary of the foundation in Lagos state, it is assumed that the information gathered is representative and hence relevant for this study.

5. Results and Summary of Findings

This next chapter is based on the results and findings of the research and qualitative expert interviews carried out in Nigeria. It gives light to the present situation of sickle cell disease in Nigeria and explains why it is a major public health concern. Influencing factors and challenges are described and the problems individuals and families affected with sickle cell disease are faced with will be highlighted. The extent of work being done and efforts made so far by health workers, NGOs and the Nigerian government as well as the need for more assistance and advocacy will be shown in this chapter.

The following answers are classified according to the categories built.

5.1 Sickle cell disease in Nigeria, influencing factors and consequences

This category includes the following questions:

- What comes to your mind spontaneously when you think of SCD?
- Do you think SDC is a public health issue? If so, why? And what are the consequences for Nigeria?

The following responses show how the experts perceive sickle cell disease.

One of the experts said:

> *"I think of superstitious beliefs. A curse caused by witchcrafts. It is a disorder with a great lack of information of the public. Many don't know what it is and many don't accept what it is"*

Another mentioned Ignorance, mismanagement of pain and stigmatization.

Sickle cell disease was described as *"a queer torture disease",* a disease that has taken many lives, mostly due to improper care and management.

The disease is associated with death.

> *"Death, they die. It is an unfair thing to bring them to this world knowing the consequences. Many still don't know about it though"*

This expert views sickle cell disease as one that involves suffering.

> *"It is an inherited disease. It is a disease inherited because parents were ignorant or stubborn. It is a disease in which the patient suffers. The patient has to suffer crisis, absenteeism, and many social effects"*

The lack of resources to facilitate proper care and research and the effects on the individual were also mentioned.

In summary, the experts generally regard sickle cell disease as one that many are ignorant about, a disease that brings about superstitious beliefs, social stigma and discrimination. It is a killer disease that causes pain and calls for pity and is responsible for many unnecessary deaths in the country.

The next part of this chapter shows why sickle cell disease is considered a public health problem in Nigeria and what the consequences are.

One expert said sickle cell disease is rampant in Nigeria.

> *"Yes it is a public health issue. I see loads of patients with the disorder every day. There are so many, the prevalence is so high. I am always amazed when I go to our clinics"*

It as a public health issue because it is a disease not attracting the necessary efforts.

> *"It is a public health problem because there is no publicity, no advocacy and no government involvement in the fight to eradicate or prevent the disease…"*

The socio-economic and psychosocial aspects of the disease and what consequences these bring about for those affected were also mentioned by one expert.

> *"Yes, it is a public health problem. Socio economic consequences like the cost of looking after the children is a big burden. So many man hours are lost. Many parents take sick leave from work, not because they are sick but their children are sick. Then the pains the sufferers go through themselves. There are broken marriages, wives are blamed, husbands do not understand. The sicklers themselves might not want to come out and speak, because they look sick. They are afraid of the stigmatisation"*

One expert spoke of the effects and consequences of sickle cell disease on different levels. On the individual level,

> *"It is a disease that brings about pain, psychological strain and social stigmatisation. It disrupts the pursuit of life endeavours, socially mentally and physically"*

On the family level,

"It is a disease that could lead to multiple deaths of siblings. It imposes physical, emotional and financial stress on family care givers. Sickle cell is a disease that breaks up families"

On the community level,

"It is a disease regarded with taboo by the community. A sickle cell sufferer is looked on as lesser than others. There is social-stigma"

Lastly, on the national level,

"It is a disease which has brought about immense death rates, frequent hospitalisation and economic burden"

Another expert made the following contributions concerning prevalence.

"Mortality keeps rising as a result of ignorance. The more people are getting together and marrying, the more people die and so the higher the prevalence"

"Another consequence is that Nigeria has the highest prevalence of sickle cell disease in the world. The country has a bad reputation health wise. When there is a government, such problems should not arise"

In summary, the experts view sickle cell disease to have various and vast consequences. It is a disease affecting the country on different levels. It brings about physical, psychological and economical strain for the individual and families affected. It has socio economic and reputable effects on the country. Incidence rates, mortality- and morbidity rates keep rising.

5.2 Health services and organizations for Sickle cell disease

This category includes the following questions:

- What is your view on the stand of the Nigerian Health System in the fight against sickle cell disease?
- What problems / limits do you think could arise in developing an efficient intervention scheme for sickle cell disease in Nigeria particularly?
- Do you know of any governmental *programmes* or co-operations for sickle cell disease in Nigeria? Which? / How do you find the quality of these programmes? / Is there any room for improvement?

- Do you know of any NGO programmes for sickle cell disease in Nigeria? Which..?/ Do you know any of their projects? / How do you find these? / Is there any room for improvement?

(Question particularly for Experts from Sickle cell organisation)

- When planning a new project or awareness scheme, are there any guidelines or recommendations or existing concepts from other countries you (your organisation) follow(s)?
- Does your organisation have cooperating partners in other country's or in other world-, or African organizations?

In regards to the involvement of the Nigerian health system the following remarks were made:

> "*It is below standard. It is terrible, even among doctors, there is not enough education. Basic drugs which should be free cannot be made available. There is no counselling, it is totally inadequate"*

The need for co-operations and partnerships between the private sector and the Nigerian health services was mentioned.

> *"The Nigerian Health System is not doing much, and I don't think they should be left alone in this matter. I think there is a need for more cooperation, more private partnership, people who have personal interests in this issue can form partnerships with the Health system"*

An expert spoke of the "sickle cell advisory expert committee" which was set up about a year ago. This committee presents a means of reaching out to the government.

> *"…It is a committee addressing this issue and set up to advice the government and share experiences on sickle cell disease. The government needs advice on the health system"*

The need for further training and education for doctors, which the health system could support was mentioned.

> *"The Nigerian Health System is yet to embrace it. Sometimes even doctors have not been enlightened. They send Sickle cell disease patients away without any advice and tell them to only come back if they have a crisis. To get help and support from parties that are not personally interested is difficult. I think the Health system has not yet seen the need to come in"*

The lack of involvement of the government is strongly commented on.

"It is far below expectation, it is not enough. The system has failed. There is unjustifiable negligence"

Another expert finds the attention being given to sickle cell disease by the Nigerian government and other Non Governmental Organizations too little. He also feels that it has not yet become a priority.

"The Nigerian Health System is not doing enough. There is more publicity given to HIV and Tuberculosis. Half the attention is not even given to sickle cell disease. There are too few NGOs, they are doing well but more efforts are needed. The health system could do much more"

The involvement of the government is perceived to be stronger in the cities and developed areas of the country. Rural areas remain neglected.

"Well, the little they are doing is mostly in urban areas. Villages with less educated people are not aware of the disease. Some have never even heard of such a disease and don't even want to hear of it. Health programmes are easier to access and plan in the cities"

One expert however feels that the Nigerian health system has not regarded the situation with disinterest but is in the processing of planning intervention programmes.

"They have good intentions, plans have been made on paper but nothing is being carried out yet, at least we don't have any desired results yet"

The interviews showed that the Nigerian health system may not yet regard sickle cell disease as a priority. The experts view the level of involvement as below expectation.

As to what limits could arise when planning intervention, the following answers were given.

"It is doubtful that the government will take it as a priority, considering the present economic situation"

One of the experts mentioned mismanagement of funds due to corruption as a limitation.

"Millions may be kept for this purpose but it goes into private pockets…"

"Many organizations may provide materials and funds for this use and direction, but it will not be properly utilised. Corruption and improper Management of funds are limits"

The other experts looked at it from the point of view and mentality of the public.
One expert thinks it might be difficult to get those affected with sickle cell disease to partake in intervention activities.

> *"Most people tend to shy away from these things. Many pretend that they do not have sickle cell disease. People don't want to come out and participate, they fear stigmatization. Many have to be convinced to take part and these are not only the less educated. So even if help is offered, many might not be willing to participate, so the problem is getting to the people first"*

This expert shares a similar opinion and feels that stigmatization must be overcome.

> *"If many who are affected themselves come out, it will encourage others to do the same. Others are talking about our issues for us affected ones"*

On the other hand, this expert feels that if help is offered, people will embrace it.

> *"I think if the government comes in, the public will welcome it. There are so many Sickle cell disease affected individuals who have been rejected by the society and public, so I think they would welcome any help. This also would reduce stigmatization"*

Ignorance was mentioned as a limitation.

> *"The problem they will be faced with is ignorance. Being educated doesn't mean one is not ignorant"*

Another expert says to achieve an efficient prevention scheme everyone should know their genotype status.

> *"Everyone should know their genotype, and this is difficult because some laboratories give people wrong results. They don't have the right equipment to carry out tests but still want to keep their customers.*
>
> *Then there is too little awareness. So knowledge must be promoted. I think we need to lay out all the cards down, embrace and accept the situation and let people know what they can do. Choices arise after people know what it entails"*

A major problem is seen in the taboo mentality concerning sickle cell disease.

> *"Alarm fatigue and taboo mentality will arise. Health care workers are affected by this. No one is ringing alarms. This taboo-mentality makes it look like a no-go area. People need to wake up to reality and see that sickle cell is a major problem. When they do, people will start budgeting and creating committees"*

In summary, the problem of corruption and funding seems to play an important role. A few of the experts showed anticipations towards how the public, especially those affected would receive prevention and awareness campaigns. The other experts view public education as a vital measure in creating efficient prevention schemes. This would immensely reduce stigmatization, what many fear.

When asked on the knowledge of government organizations for sickle cell disease, five of the experts did not know of any such organizations.

"No, "make that a big No". I know of nothing, no co-operations"

"No, I do not know of any governmental programmes or organizations"

One of the five however mentioned the involvement of the government concerning the controlling of new drugs for sickle cell disease brought into the Nigerian market.
Two of these experts knew of the Sickle Cell Centre in Benin City. They however thought it was an NGO.

Other three experts knew of the sickle cell organization in Benin City and that it is a governmental organization. Of these three, one spoke about some hematology clinics in university teaching hospitals and tertiary institutions run by the government. The last of the interviewees knew of some awareness and genotype screening programmes sometimes organized by the government. This expert however could not give any definite names or precise details of these organizations. The three experts who knew of the Sickle Cell Centre in Benin City were asked if they knew of the projects and if they feel there is a need for improvement. All three specified the need for improvement. They mentioned the lack of funds and facilities and the need for more advocacies.

The experts were asked on their knowledge of NGOs for sickle cell disease. All experts knew at least one NGO in Nigeria. The Sickle Cell Foundation in Lagos and sickle cell clubs are known among the experts. Three mentioned screening and awareness programmes organized by NGOs they knew of, sometimes held in Universities, schools, market places and so on.
When asked about the quality of the projects, some mentioned programmes run by the Sickle Cell Foundation in Lagos. One expert spoke of some educative programmes he knew of, organized by the foundation. These were about coping and management strategies for affected with organ damage.

The experts, those working in the foundation and others however, all stated the need for improvement. Improvements like the need for more staff and facilities to equip the laboratories. For example the need of a polymerase chain reaction machine[8] (PCR machine) for DNA analysis. These improvements however depend on available funds.

One of the experts working in an NGO was asked if the organisation follows any concepts or recommendations from other countries when planning intervention programmes and if they have co-operations or partnerships with other countries.

"We follow the goals and aims of WHO. Their recommendations are like guidelines but we are far from there"

"There are groups of people, individuals interested in this topic. They show interest, some make donations. The "MTN" foundation has helped very much with donations and funding. Organizations meet from countries all over the world to discuss progress. We are still behind. These organizations could help more. Unicef could help, a lot depends on personal interests too. For example, a WHO director might not be particularly interested in sickle cell disease, it all depends"

5.3 Public health and intervention

This next category is about public health and intervention measures. The following questions were included:

- What are realistic goals which can be achieved with an optimal sickle cell awareness and prevention scheme? / If you had the resources to change anything and improve the present situation of sickle cell in the country, what would you change?
- What institutions would you personally see as good mediums to support awareness and prevention schemes?
- What is your view on genetic counselling for engaged or expecting couples?

The following responses were given:

"I think if free drugs can be provided, a lot can be achieved. There should be proper education for doctors. I think sickle cell disorder should become an area one can specialize in while practicing medicine. As there is a faculty for gynaecology so also there should be one for sickle cell"

"I would find a way of helping them cope with the emotional issues"

[8] A technique used to determine hereditary diseases. It can differentiate between sickle cell genotypes

This expert gives some suggestions of important goals to be considered.

"*Convert this disease from a killer disease not compatible with adult existence to a chronic disease like hypertension or diabetes. As long as they adhere to their limitations and rules, they can live well with the disease.*

Other goals are more training for doctors and nurses, there should be training programmes for clinical psychologists. More individuals and organizations should be stimulated"

Reduction of death rate was also mentioned as a realistic goal.

"Death rate would reduce. There would be an impact on the economy, more healthy people to work. And the child is spared the trauma of living with the disease and the conditions. If I had all resources, obviously I would eradicate the disease. I would provide education for all and pass the message across to those who cannot be reached"

Changes that could be made with the available resources included the following:

"Reduction in incidence rates of SCD in the country, reduction of suffering of the sickler by prompt attention medically and socially. I would put more money into more projects and encourage more research"

"To have an effective prevention scheme, there must be an improved primary health system which is presently lacking in the country. General counselling facilities will be needed. To even carry out a big prevention scheme like this, a lot will be needed like management of the funding, logistics and so on"

Most of the experts mentioned the availability of free drugs as what they would change.

"I would subsidize the prices of drugs and make them available to all"

In summary, a reduction in incidence and mortality rates was seen as a realistic goal that could be achieved. This would be through education, awareness campaigns, training for genetic counsellors, and through improved management of the disease and health facilities

The experts were asked how they would increase awareness. Many mentioned the media i.e. television, radio etc. Clinics, hospitals and NGOs were mentioned as well.

Three of the experts suggested the integration of sickle cell disease into the learning curriculum in schools as an early intervention strategy.

"Introduce it as a topic into curriculum at secondary schools"

One of the experts spoke of educative programmes on Television. Not just advertisements but a talk show that could take place regularly, in which the public would be educated about sickle cell disease.

The importance of field work was also mentioned.

"I would increase awareness through field work. I would go out into villages, markets and schools. Personal contact goes a long way. Not all people have TVs. Even those who have, hardly watch news or educative channels, at least the youth don't"

The involvement of churches as a means of spreading awareness was mentioned.

"Churches; many churches ask for genotype tests before allowing couples get married, so the couple know their status. I think it is a way of spreading awareness"

These answers showed that to increase awareness, public education must take place first. This is best achieved through genetic counsellors, health workers as activist, clinics, health service centres and the media. It was also said that an ideal way to educate the public would be to start from childhood i.e. in primary and secondary schools. The involvement of churches that request genotype tests from engaged couples was also commented on as a means of spreading awareness.

The experts were asked what they thought about genetic counselling.

"It lets them know the possible results and prepares them for possible consequences. Couples should undergo pre tests and post tests counselling on hemoglobin genotypes. Some decide not to marry anymore. It gives them choices"

"It is good, it helps people understand and have choices"

One expert spoke of the ethical aspects to it.

"It's a good idea. People should know what they are doing. Personally, I don't believe in prenatal diagnosis, because it is an ethical matter, I am not for it. But those who go for general counselling should know their chances and whatever they decide, they must be psychologically prepared"

Another expert contradicts this.

> *"Ethics is made by man. It is what you call it. The ethics of bringing a child into this world to suffer, is more that the ethics of aborting the child"*

This expert also stated that not many can afford a prenatal diagnosis. Research showed that a prenatal diagnosis in Nigeria presently costs 400 000 Nigerian- naira. This is almost 3000 US dollars. For this reason, effects of prenatal diagnosis so far on prevalence rates cannot yet be examined in Nigeria.

In summary, genetic counselling is regarded as a good means of educating people on the disease, particularly sickle cell carriers. However the discussions on ethics showed that it is a rather delicate matter that obviously must be approached sensitively.

5.4 The individual and influencing factors typical for Nigeria

This category entails the following questions:

- How would you describe the situation of sickle cell affected individuals? Health wise and socially?
- What of SC carriers? How do you see their situation? Health wise and socially?
- In your opinion, what factors reduce the life expectancy and quality of life of sickle cell disease affected in Nigeria? Compared to some developed countries where sickle cell affected have higher life expectancies and a better quality of life.

(Question for medical doctors)

- Many patients with sickle cell disease take pain killers regularly. These have negative aspects and could lead to an addiction. What do you think about this?

Regarding the health situation of sickle cell affected individuals, the experts gave following responses.

> *"It depends on the individual. People have different disposition and genetic make up. Just like people with AA react differently to different things, so also those with SS react differently. Some have leg ulcers, others don't. It varies. It also depends on the socio economic status of the persons affected and the level of awareness"*

One expert said with all provisions from health services, the person can live a healthy life as long as they adhere to the dos and don'ts of the disease. However the psychosocial factors play an important role because if there is no support from the parents or family and friends, it is very difficult to cope with the disease.

"Mortality has risen from disease-factors to psychosocial-factors. The disease can be treated and managed but social factors play a powerful role"

The health wise situation was described as grave.

"It is living in hell on earth. The prognosis is not as bad though but all in all the effects of sickle cell on the patient is still below any tolerable level and is a big burden…"
"Many live in fear that they will die prematurely or die anytime… they experience inter-phases of falling sick and being healthy. Today football and tomorrow blood transfusion"

On a social level, the experts spoke of stigmatization and discrimination.

"Every one looks at them with pity, they are seen as helpless and incapable to be left alone. It affects them psychologically"

"They are socially discriminated because of stigma"

Problems that may arise within the family were also mentioned.

"They get more attention in the family. Other siblings might get jealous which could create family problems"

This expert spoke of possible personal consequences of having sickle cell disease.

"Many face stigmatization. Some are abandoned by family, after a while they refuse to help their children, because they see no results and feel their money is being wasted. I have had a few cases, where some say they are called all sorts of names by their family or their father abandoned them. One told me recently his parents refuse to send him to university because they said he will soon die anyway. So I think ignorance still plays a very important role in their lives"

An expert spoke of the *"health care giver fatigue"* and *"faith abuse"*.

"They are disadvantaged. There is the health-care-giver fatigue. For example, some get abandoned from their parents or the husband leaves the family, because he blames the wife for the sick child. This is part of ignorance. Some unenlightened parents do not allow their children have blood transfusions, because of religious interferences. I call it faith-abuse. They deprive them of medical care and rather pray for them, while the child is in excruciating pain"

In summary the social and health situation of sickle cell affected was seen as disadvantaged. Research in Nigeria also showed that some people are discriminated from getting jobs because of their genotype status. This was mentioned in some random discussions with other interviewees.

The sickle cell carrier's health situation was regarded as fine and normal. Two said in very rear cases, they had heard of carriers having minimal crisis.
Socially, their only limitation was in respect to the choice of a future partner.

> *"A few always have on the back of their mind "I must marry someone with AA" I know of a woman wit AS who did everything to marry someone with AA and he turned out to be a wife beater. So I think it's about being informed, people should know what the stakes are, what they can encounter and what can be done. I tell a few if you cannot cope, then please for the sake of the children you will have, don't come together. The most important thing is that they are well informed and they know what they are going in for"*

> *"They might only have a fear of their future partner, because of the genotype"*
> *"They are sensitive about who they marry"*

When asked about what factors the experts think influence the quality of life and life expectancy of sickle cell affected in Nigeria, different factors were mentioned.

> *"Poverty, ignorance, lack of health care facilities, affordability of health care, rejection, abandonment, stigmatization, discrimination and religious bigotry"*

> *"Well, it depends on the socio- economic factors like I said. Then, poverty plays an important role too. Those who have a lower standard of living will not be able to take care of themselves as much as those who have a higher standard. That is why the sickle cell clinics are important too because they are helping to give free care and free drugs. I think it is the lack of awareness and lack of support from the government so far that are playing a particular role in the situation in Nigeria"*

> "*Well, typical for Nigeria is the stress. People get into so much stress, we get stuck in traffic for so long and there is no electricity. There is no health sector assisting, for example if you are having a serious crisis you can't even call an ambulance. Those who are poor have no choice than to visit all these quack doctors, who give them the*

wrong medication. For example some are even allergic to certain drugs and they get such drugs prescribed"

"There are no government policies. There are no research institutions"

One expert mentioned the lack of infrastructure as influencing factors.

"Infrastructure. For example in countries where there is a crisis, you can call an ambulance fast, care is given fast. Here you are left alone. There is lack of clean water, there are mosquito bites, electricity problems and so on. There should be more psychologists, home visits should be paid, more clinical social workers. Screening for newborn babies should be a standard procedure"

Generally, socio-economic factors like ignorance, the lack of government intervention and adequate health care facilities were all mentioned as factors that decrease quality of life and life expectancy of sickle cell affected in Nigeria.

Some of the experts were asked about the pain medication taken by the sickle cell patients and possible negative effects like addiction. One expert said addiction could be a problem and spoke of the search for pain management remedies like medication without addictive analgesics[9]. Many may also abuse drugs because of ignorance or interference with traditional medicine.

5.5 Future prospects

This category includes these questions:

- What do you think is the most important aspect to be considered in the prevention of sickle cell disease in a country like Nigeria?
- Considering all what you have said how do you see / estimate the situation in the future? Let us say the next 7 years.

The experts mentioned awareness through education and public enlightenment, research and more training of genetic counsellors and health care workers as the most important aspects to be considered when planning prevention in Nigeria.

"The most important thing would be to keep on training health care workers and creating awareness. Then include it in education in schools and create general publicity for it. Enlightenment of the public, promote more genetic counselling and very

[9] A diverse group of pain killers

importantly research, more research should be supported. All this is necessary to manage sickle cell better"

"Education, teaching about the disease. It is not contagious. Simply education"

The need for government policies was mentioned.

"Government policy. If we had a viable policy on it there would be a difference. There could be planning but there is no execution. A lot is on paper but it must be executed first. There is need for effective policy. When policies are made, financing will start, budgeting will start"

"Training for genetic counsellors"

"Counselling, more education"

"Eradicate Malaria. That is the most important aspect"

In summary, the need for education, counselling and the involvement of the government were mentioned by most experts. One however said that the eradication of malaria would go a long way in reducing incidence and mortality rates. All these were mentioned as important aspects to be considered when planning public health intervention measures.

When asked about how the experts estimate the situation many mentioned government involvement.

"There should be an improvement, awareness leads to people seeking proper treatment. I think some light will be brought to the whole matter. Awareness brings light for many. Having SCD is not the end of the world and that is the importance of all these sickle-cell clubs, to spread the word and make people understand. I think in the next 7 years, stigma will be reduced too. With the awareness, proper disease management will come in. Improvements will come. I feel the government will have a part to play then"

"I think there will be more support from the government and if we have their assistance, then we would have achieved a lot"

"There should be an impact; I hope to see more sickle-cell centres, more clinics. More people should be coming in to clinics for prenatal diagnosis. There should be more

interested NGOs. I would expect little but significant input from the government. Maybe a legislation, like each state must have a centre and a clinic"

These responses were also given:

"Lame prospects, hardly much, but there should be more change. People should wake up, alarms should start ringing"

"It should be brighter. The light is already at the end of the tunnel, but we aren't at the end yet. The government must put more resources to help individuals"

"There should be a reduction in incidence and mortality rates but it will not be so significant or tremendous. Because the government interest is on tuberculosis and HIV, the focus might only slowly come on SCD. Thinking that this is something that cannot be treated, most government bodies might not be too interested"

"It should reduce fast. Many people received the HIV campaign well, so if Sickle cell gets that attention I think it would go a long way"

The need for the involvement of sickle cell patients was seen as a factor to stimulate a change.

"I don't want to be negative, but unless we SS people come out, nothing will happen. The change has to start from us. Until we come out and there is a cry for help I don't see the government coming in because they will not see the need. So until more people come out and talk about their own problem and not let others talk for them, I don't see much happening"

Generally, the interviews showed that any significant changes in the future would be mostly dependent on government involvement and massive public education. However, expectations concerning government intervention are not overrated since government support and attention is expected to remain far behind HIV and tuberculosis.

5.6 Others

In this category, the experts were asked if they had any final contributions they would like to make. Some of the following comments were not only made by the experts, but by some other random interviewees the researcher had discussions with.

"A lot of research is needed. It should not be the responsibility of the sufferers. It is a social responsibility. This taboo mentality must be overcome"

"Sufferers of sickle cell disease should be given enough love and care because they are not responsible for their problem. If possible, the government should provide most of their needs for them, like free drugs, free hospitalisation and free education"

"There was a day a girl at the university got her crisis. It was late at night in the hostel. We couldn't get any help. She cried all night. Her friends were rubbing her arms and legs. She suffered. It was bad. I wouldn't want my child to go through that"

"My younger brother died of sickle cell disease in 1996, he was 14years old"

A young man was asked what he knows about sickle cell disease. He said he just knew *"something was wrong with the blood"* but he did not know much.

In a discussion, a man said:

"I know of a family friend who lost three of her children to sickle cell disease"

One of the experts said she knew a few sickle cell affected individuals who are well over seventy years old and are living healthy and normal lives. They are a motivation to her.

This expert said:

"I think you are doing a good job. People need to come out and do more for sickle cell disease in Nigeria"

6. Discussion

The discussion in this chapter is focused on the assessment of the results and findings of the expert interviews and based on the research carried out in Nigeria.

Sickle cell disease has been present in Nigeria for a long time. The prevalence rate is rising and so also the mortality rate. In other developed countries where sickle cell disease is present like in U.S.A. the prevalence rates among blacks are gradually reducing, because of the availability and access to the proper health services, public awareness and so on. The reasons for this high prevalence- and mortality rates in Nigeria were investigated and the results showed that there are many influencing factors.

According to the interviews, such factors include ignorance, lack of public interest, the lack of proper health care facilities and services, lack of government involvement, malaria and stigmatization as well as socio-economic factors like poverty, lack of electricity and access to clean water. Lack of awareness and misconception in particular were shown to lead to high prevalence- and mortality rates and stigmatization.

Low awareness and misconception concerning the disease

From the results of the interviews, sickle cell disease is a disease not known or misunderstood by many. Ignorance or lack of education has resulted in false views of the disease. Due to the course of the disease when not given the right care, many see it as a disease that almost surely leads to death.

Many affected individuals often have crises and are consequently frequently hospitalized. They may not make visible improvements. Others do not understand this and it therefore leads to superstitious beliefs and stigmatization. In some cases, this has lead to the health care giver fatigue (when families get tired of financially supporting their affected children). Also, because many think sickle cell disease cannot be treated or properly managed, it has resulted in a hopeless disorder attracting only little public efforts and attention.

Many people in Nigeria do not know their genotype status. Couples who are carriers of the sickle cell trait may not know this and get married and have children. They are not prepared for the consequences; they may not understand the origin of the disease. Research showed that even when the hereditary process of sickle cell disease is explained to some well educated people, they find it difficult to understand or accept it.

The interviews also showed that many marriages have been broken up due to the presence of sickle cell disease in the family.
Also, many affected, particularly adolescents find it difficult to cope with the psychosocial factors of the disease. Compared to their peers, puberty is often delayed in sickle cell affected adolescents (Koshy and Dorn 1996). Young girls may start their menstruation later than most of their mates. Some have worries of never getting married and having children. Many fear premature deaths and some think of suicide. The families are also immensely affected. Parents may have lost more than one child to sickle cell disease or are afraid of losing a child. These are some examples of psychosocial aspects of sickle cell disease that need to be addressed and integrated into intervention programmes.

The lack of information, publicity and proper education on the disorder has brought about ignorance and stigmatization.
It is therefore left for the relatively few health workers and activist involved to change this public perception. This is why the experts emphasized on the need for government involvement to have a larger scale intervention.

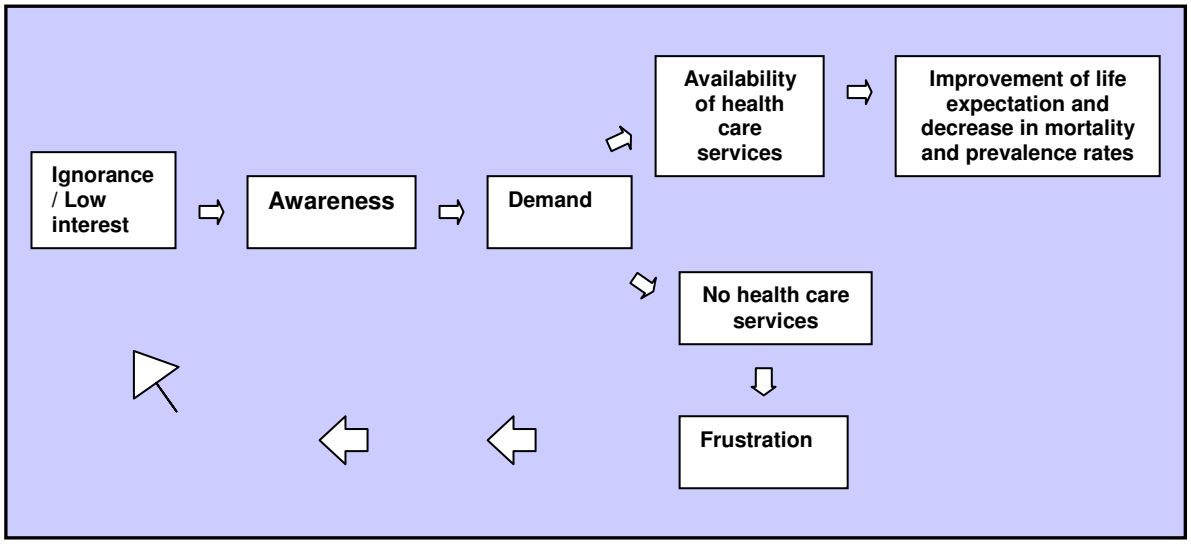
Lack of appropriate health care services

Awareness alone is however not enough; there needs to be the necessary help awaiting people after they have been made aware. If awareness is raised, it calls for a demand. The attention of the public will be awakened, and the next step for them is to seek help from health care services. This seeking of help may demand genotype screening, hospitalization, provision of medication, provision of counselling and education on the management of the disease. It may demand house visits, psychological support and counselling for families and individuals. It may also demand health care support in schools attended by children with sickle cell disease.
If these demands cannot be met, it creates frustration amongst the people and whenever prevention of sickle cell disease is mentioned, a disinterest will arise (See figure 6).

Hence before awareness programmes and campaigns are planned for, awaiting health services must be made available.

Figure 6

Figure 6 illustrates the awareness cycle explained above.



The consequences of sickle cell disease in Nigeria were stated in the interviews. They are numerous and immense. Considering the amount of deaths resulting from sickle cell disease alone, there should be more health care services and specialised clinics in the country.
There are many patients who cannot afford their medication or do not have access to this. There is a need for availability and accessibility of drugs.
A patient cannot get proper care in every clinic, because not all nurses or doctors are trained to give specialised care or treatment to sickle cell disease affected. Many patients are sent home without advice on their lifestyle and asked only to come back when in crisis. Those in rural areas may not be able to get immediate treatment because there are no nearby clinics.

Poverty plays a vital role in many lives, both healthy and unhealthy. Those with a lower socio-economic status may not be able to provide more than one meal a day or a balanced diet for their children. Lack of access to clean water and interrupted electricity supply are problems typical for Nigeria which affect the lives of sickle cell disease patients. If an environment is dirty or the water is dirty, it allows for mosquito breeding which eventually brings about malaria, a danger for sickle cell affected.

If proper care is taken, the amount of crises in an affected person's life could be well reduced. Because of lack of education on the disease or a low socio-economic status, those affected cannot take care of themselves properly. For example many self administer iron because they think it will increase their blood count, they are not aware that this has a

counter effect. Others may not drink enough fluids because they do not know it will help them or because they do not have access to clean water.

The mismanagement of pain poses a threat in the lives of many affected individuals. This may be due to self medication. Either they are given the wrong treatment at home because the family does not know what to do or in hospitals the necessary medication is not available. Sometimes drugs may be administered which are not compatible with the patient. There is a need for more research and training on pain management alternatives.

The government has been making efforts to introduce sickle cell medication into the Nigerian drug market. In 2006, a sickle cell drug called "Nicosan[10]" was launched by the federal government in Nigeria[11]. The government also has some partnerships with pharmaceutical companies for further research and development of medication for sickle cell disease. These are efforts that should be encouraged and further developed. However, when the magnitude of the sickle cell situation is compared to the present efforts made by the government, the efforts seem quite minimal. Intervention measures should be focused on both preventive and treatment/curative measures.

Furthermore, there needs to be more research and development of clinical care for complications caused by sickle cell disease such as priapism or the combination of sickle cell disease with other diseases like HIV or hepatitis due to blood transfusions or other reasons.

Another important factor that needs addressing is the lack of surveillance and monitoring of the disease in the country. If intervention measures were to be implemented, there would be a need to follow up the proceedings. Improvements cannot be determined without surveillance. To properly manage the disease on a national scale it is necessary to know where it is most prevalent, for example in which geographical region and among which cultures, socio-economic and educational background (if there are discrepancies). To follow up incidence rates, newly borne with sickle cell disease will need to be registered in hospitals and clinics. This is however dependent on neonatal screening and may exclude house births. These infants born at home could be registered in centres and then be screened for their genotype. Through such measures, the situation can be monitored and facts derived which will help plan further intervention measures.

---

[10] Nicosan is an anti-sickling herbal drug developed by Nigerian pharmacists

[11] http://www.redorbit.com/news/health/566714/nigerian_president_olusegun_obasanjo_launches_xechems_sickle_cell_drug_nicosantm/index.html

In general, there is an urgent need for an improvement of the primary health care services in Nigeria. An improvement would depend mostly on large scale funding and management of funding by the government. However until sickle cell disease is recognised by the government as a major public health concern needing immediate intervention, no magnificent changes may occur.
With the necessary funding and management, the health care services could be improved. Facilities to support neonatal diagnosis could be acquired, medication and hospitalization for sickle cell patients could be made free or the prices subsidized. Frequent medical check ups could be encouraged and integrated as part of an intervention measure.
Funding would support the development of sickle cell clinics and hospitals to give specialised care to sickle cell disease patients. University teaching hospitals which are run by the government could also be further developed. The equipment necessary to teach young doctors and nurses may be lacking, and hence not allow them have the necessary exposure.

From all information gathered during research, there are small scale improvements on the situation. Some of the experts (medical doctors) interviewed said that many have reported to have a better health status since the use of certain drugs available on the market. One expert said that since the foundation in Lagos was set up and work started, improvements have been made in some patients' lives. The amount of blood transfusions given in the sickle cell clinics this expert is aware of have reduced visibly. It was also stated that those who follow the doctor's orders have made visible improvements.

This shows that positive changes can be made and many will welcome help. If clinics could be set up all over the country, most people would be able to access these clinics and thus have the medical support they need. This however depends on the government.

7. Recommendations and Conclusions

This paper has shown various consequences and challenges brought about by sickle cell disease in Nigeria. This chapter presents recommendations addressing these problems and influencing factors.

Creation of awareness and public education

Public education was stated as one of the most important factors when planning awareness schemes. Here, there is a need to split the focus of public education. On one hand the focus should be on education of the affected and their families to improve treatment and management of the disease and on the other hand there is an immediate need for a drastic increase in awareness of the general public in order to implement preventive measures. The general public here includes 24% carriers of the trait who in many cases are not even aware of their genotype.

To raise public attention, the first step is to create awareness through aggressive campaigns. Awareness can be increased through media, like TV and radio advertisements, newspapers, talk shows and billboards. One of the experts reported that airtime had been bought on a TV channel. Once a week there is now a programme on sickle cell disease. Affected individuals could also come to these shows and share their personal experiences. This would also encourage others affected to feel more comfortable with their disorder and less stigmatized.
Similar awareness campaigns have successfully been carried out in Nigeria for HIV (BBC World Service Trust 2008). A campaign for sickle cell disease can be set up and implemented according to the HIV model profiting from synergies. These could for example be by way of co-operations with HIV organizations to profit from their already implemented structures e.g. Village counselling every six months, in which the sickle cell advisers could join in meetings and educate the target groups. Another advantage is the fact that available data on funding, resources and efforts could be used as a benchmark or orientation point for the planning of an awareness scheme for sickle cell disease.

Through field work in public places like markets, schools, universities and educational institutions, people can be reached through health workers, genetic counsellors and activists. The interviews showed that personal contact is important to create awareness, because many young people may not watch educative programmes on television or listen to radio and not everyone has a television or radio at home.

It is important that field workers speak the native language of the people they are trying to reach out to because Nigeria is a country with different cultures and languages. When spreading awareness in rural areas, where some are uneducated, this helps people to understand better and trust the field workers more.

Public genotype screening could also be a means of reaching out to people. This could take place in market places, rural areas (like villages, centres or squares), health centres, schools, universities, work places and so on. It could be integrated into awareness campaigns with a catch-name like “know your name and know your genotype”. Through such a campaign, many would become interested and informed of their genotype status and thus inform themselves further.

Churches already play an important role in creating awareness. Before a couple is married by the church in Nigeria, most churches request they carry out HIV and genotype screening. This is to ensure that the couple is fully aware of their health status before getting married. Churches play a very important role in Nigeria, as about 40% of the population are Christians (U.S. Department of state 2003). This procedure is hence a very important step in creating awareness and should be encouraged further. If a couple finds out they both have the Hb “AS”, the church could refer them to a sickle cell clinic or health centre, where they could get further information and be counselled. Sickle cell organizations could proactively contact churches to encourage this practice.

Integration of sickle cell disease into the learning curriculum in primary and secondary schools could ensure education at an early stage. It could either be introduced as a topic in a subject like general science or health workers could come in regular visits to talk to the pupils and students about sickle cell disease.

Clinics, sickle cell clubs, hospitals and health centres can act as information- and counselling centres. Consultation hours should be made available for counselling purposes and advertising should be carried out in clinics for this. If two sickle cell carriers find out their status, they should be able to get genetic and psychological counselling preparing them for whatever decisions they make.

Education of sickle cell affected on self care and management of their disorder should be integrated into public health education schemes. The above points have focussed mainly on the education of trait carriers and “healthy” people to improve prevention and reduce

stigmatization. However ignorance and illiteracy among affected often lead to wrong treatment or care and also need to be addressed.
To enhance and support the education and counselling for affected, comprehensive sickle cell disease programmes should be established. These could be programmes or courses set up to update or educate affected on current and prophylactic treatment measures, anti-sickling agents and improved management techniques or alternatives. An early involvement of sickle cell affected in such programmes would focus on an improved quality of life.
It should be a social responsibility of health care providers and physicians to encourage patients to participate in comprehensive sickle cell disease programmes; seek preventive medicine aspects of health care and select health oriented life styles, education, vocational and social skills so as to be able to live normal lives (Koshy and Dorn, 1996).

To carry out these measures mentioned above, sickle cell clinics / centres and clubs need to be set up in different parts of the country. This requires more government involvement and NGOs. More genetic counsellors, doctors, nurses and health workers will need to be trained to give specialized care in these clinics. This would require work force capacity building. Recommendations from the WHO on prevention and management of sickle cell disease could serve as a guideline for setting up such intervention measures.

The Need for government involvement and funding to support intervention measures

Provision of proper facilities and equipment: To manage sickle cell disease in Nigeria, the proper facilities and equipment are required. For example, to get definite results from genotype screening, a Polymerase chain reaction (PCR) machine is needed. Such a machine is expensive and cannot be provided by all health institutions. Acquiring such equipment is dependent on available funds. Many private clinics and NGOs are dependent on donations and private sponsorships. Their limited resources may not allow them acquire the necessary equipment they require. If sickle cell clinics, hematology clinics or health centres were to have enough PCR machines and become accredited for this, genotype screening could take place in masses in these clinics. With the necessary funding, this screening could be made free or costs subsidized so that the poorer population could afford it. If such clinics or centres could present such offers to the public, many would no longer visit any kind of “quack” laboratories which may give out false results.

Neonatal diagnosis should be integrated as a standard measure in every hospital or clinic where a child is born in Nigeria. With funding and legislations, it could be made free for all infants in the university teaching hospitals and general hospitals.

Prenatal diagnosis is another preventive measure still being developed in Nigeria. It is however relatively expensive and can only be afforded by few. If the cost of this prenatal diagnosis were to be subsidized through government intervention or other private funding, it could be made affordable for more expecting couples. The advantage of this prenatal diagnosis is that it is an early intervention strategy. It would prepare those sickle cell trait carriers who decide to have children for the possible consequences.

Research, surveillance and monitoring are important to set up a present sickle cell disease profile in Nigeria. If a large majority can be registered in health centres and clinics, their records could be followed up and monitored. Correlations could be examined between life expectancy rates and socio-economic status for example. With proper disease management measures, case control studies could be carried out and further improvement and management techniques developed. Surveillance and proper monitoring could determine in which states, cultures and geographical regions death rates are higher and why this may be. Possible remedies or management options could thus be customized to fit into the lives of those living in these regions.

The long term effects of intervention measures (such as public education, awareness campaign measures, neonatal screening, disease management and so on) could be compared with mortality and incidence rates to see if and how much improvements have been made. This can be made possible with surveillance and monitoring.

Further research is necessary for the development of efficient disease- and pain management techniques and alternatives. In Nigeria there are various available herbal medications that “claim” to slow down the sickling process of red blood cells. According to some of the interviewed experts, different patients say different medication work for them. Research is necessary to determine which of these medications may be placebo drugs, and which of them really have positive impacts. Furthermore research is required to develop and improve these medications.

All these research and surveillance measures are dependent on the available funding which should be ideally provided by the Nigerian health system.

Malaria is an important factor to be considered when preventing sickle cell disease in Nigeria. Malaria poses a threat to many lives in Nigeria. About 300,000 children under 5 years of age die from malaria every year in Nigeria. One expert said in the interviews that the first step in the fight against sickle cell disease is to eradicate malaria. Though the eradication of Malaria is obviously still a project for the distant future, the grave effects of malaria on sickle cell affected are herewith emphasized.

The amount of malaria parasites can be reduced by keeping clean environments and appropriately disposing of dirty water which supports mosquito breeding. This requires appropriate drainage systems and availability of clean water supply. These are all present government projects.
In riverine areas, it is almost impossible to prevent mosquito breeding. Since malaria is therefore present in Nigeria, people can only take precautions and try to prevent it by using mosquito nets, insecticides and so on. These are measures already being implemented in Nigeria. However the importance of these measures in the case of sickle cell affected could still be emphasized more.
Government schemes could furthermore include the provision of or subsidization of malaria prophylaxis for sickle cell affected individuals.

The need for partnerships, co-operations and advocacies.

Partnerships with sponsors are important factors to support intervention programmes. Considering the magnitude of sickle cell disease in Nigeria, this major public health concern cannot be left to the government alone. Through partnerships between sickle cell clinics, centres and clubs with private firms and organizations, sponsorships such as financial donations, equipment and so on could be made. Co-operations with media organizations would support awareness campaigns. Co-operations with international organizations as in the case of HIV in Nigeria should be targeted by the government and the national NGOs.
Furthermore, through partnerships and advocates, children with sickle cell disease from poorer families could get free medication and hospital check ups and in some cases maybe even scholarships for their education or subsidized school fees. NGOs or state governments could take this on as smaller projects.

There should be partnerships among sickle cell organizations in the country. For example between health information centres, NGOs for sickle cell disease, sickle cell clubs, specialised clinics and hospitals. Through these, patients visiting centres for information and counselling purposes could be referred to specialised clinics for proper care if the need arises. This would also support disease management programmes.

Partnerships with Sickle Cell Foundations in other countries are necessary to have guidelines, concepts and recommendations for orientation purposes.

In the fifty-ninth World Health Assembly of 2006, the WHO stated the need for further partnerships at national, regional and global levels as well as the need for high level

advocacy to ensure that governments of affected countries and international aid agencies are fully aware of the extent of the problem of sickle cell anaemia (WHO 2006a).

Provision of essential care for the individuals and families affected

Very essential is the need for psychological care and counselling services. The Interviews showed that many affected suffer stigmatization and psychosocial effects of the disease. The families are often exhausted emotionally and physically. Many may not be prepared and do not know how to cope. They need psychological support. There are many aspects which families and sickle cell affected individuals are faced with which need to be addressed. Clinical psychologists could play a part. These psychologists could train nurses and health workers on coping strategies, how to handle such matters and how to give support to these individuals and their families. There should be enough psychological support and places people can go to for such help.

The need for self management of the disease: Physicians and the health care system cannot alone provide the perfect life scenario for sickle cell disease patients. Therefore the patient and family must take responsibility in the concept of holistic[12] care. (Koshy and Dorn, 1996)

There is also a need for self help groups. These could be initiated by individuals directly or indirectly affected with sickle cell disease or could be sponsored by the government or by other organizations. Such groups could serve as a form of therapy where families or affected can go and share experiences, seek advice or get information.

Another measure should be the provision of temporary homes and shelter for children and young adults who have been abandoned or psychologically abused by their families because they have sickle cell disease. These children could stay in these homes until a solution is found. Nurses and guardians would be needed to run such homes.

A direct sponsorship of individual families in financial difficulty could be made possible. Not every family has the financial means to provide the essential care for their sickle cell disease affected child. Charitable organizations set up by NGOs and interested individuals could have partnerships with banks or other private organizations. These could act as an organization giving loans to such families or donations to help them.

[12] Holistic care entails the treatment of physical, mental and spiritual aspects / treatment of body and mind

The Sickle Cell Centre in Benin City has a telephone helpline which people can call to get medical advice and psychological support. This is a commendable service which should be engrossed by other organizations. There should be more of these helpline services. Trained health workers could receive these calls and give advice to patients that may have an emergency or need information.

Conclusively, the NGOs, the sickle cell clinics and clubs and the government run Sickle Cell Centre in Benin City work according to their capacity and resources and are already achieving a lot. However, considering the high prevalence figures, their resources are extremely limited. To achieve a visible impact on the present situation in Nigeria, a lot more must be done especially in the area of awareness and preventive measures. The support and involvement of the government is crucial to give sickle cell disease the necessary recognition and provide funding necessary to manage the disease on a large scale. Triggered by government action and awareness schemes, other NGOs and organizations will gradually be motivated to join in supporting, as in the case of HIV.

Sickle cell disease has been left unattended for too long. An alarming quarter of the population are carriers of the sickle cell trait and hence the magnitude of the disease cannot be underestimated. Sickle cell disease has a higher prevalence rate than HIV in Nigeria (2,6 million Nigerians were estimated to have HIV in 2007; World Bank 2008). Unfortunately, sickle cell disease with a prevalence of 4 million affected has not been able to attain the same level of popularity. This is probably due to the fact that on one hand HIV is an infection-based disease which is regarded as more dangerous and on the other hand that HIV is a worldwide concern.

It was only in the year 2006 that the WHO acknowledged sickle cell disease to be a major public health concern in Nigeria. Since then, only little has been achieved to increase awareness and improve the lives of the affected.

There is no doubt that it will be difficult to implement the above recommendations in Nigeria, considering the challenges the government already faces such as HIV, polio, tuberculosis, malaria, poverty, lack of clean water, interrupted electricity supply, illiteracy and others. Many of these factors are interlinked and have vast consequences.

Nonetheless, this research has confirmed that sickle cell disease is a major public health concern in Nigeria. The government must recognise this fact in order to give it the necessary attention and priority it deserves.

References

Adesola, T., “Still standing”, Lagos, Nigeria, 2004

African traditional herbal research clinic, newsletter, “History of sickle cell disease”, 2008, accessed January 6th 2009, available under http://www.blackherbals.com/atcNewsletter308.pdf

Akinyanju, OO., “Profile of sickle cell disease”, Department of Medicine, University of Lagos, Nigeria, 1989

Ballas, S., “Sickle Cell Pain, progress in pain and research management- History”, Vol. 11, p. 3 - 5, Seattle, 1998

BBC World Service Trust, “Nigeria stop HIV campaign-research and impact” accessed February 15th 2009, available under http://www.bbc.co.uk/worldservice/trust/whatwedo/where/africa/nigeria/2008/03/080227_nigeria_hiv_project_research_impact.shtml

Centre for Disease Control and prevention (CDC), “Sickle Cell Disease- 10 things you need to know”, Atlanta, 2008, accessed February 10th 2009, available under http://www.cdc.gov/features/sicklecell/

Dickerhoff, R., Journal of clinical pathology, “Haemoglobinopathies and newborn haemoglobinopathy screening in Germany”, St. Augustin, Germany, 2008, Vol.62. Nr.34, accessed February 2nd 2009, available under http://jcp.bmjjournals.com/cgi/content/abstract/62/1/34

Higgs, D., Weatherall, DJ., edited by Rodgers, GP., “Bailliere's Clinical Haematology- Sickle Cell Disease and Thalassaemia”, Vol. 11, No.1, Bailliere Tindall, London, 1998

International Fund for Agricultural Development (IFAD), “Rural poverty portal- Nigeria statistics”, 2008, accessed December 22nd 2008 available under http://www.ruralpovertyportal.org/web/guest/country/statistics/tags/nigeria

Koshy, M., Dorn. L., “Hematology / oncology clinics of North America- Sickle cell disease- The Adult Sickle Cell Clinic”, Vol. 10. No.6, USA, p.1266, Saunders, 1996

Koshy, M., Dorn. L., “Hematology / oncology clinics of North America- Sickle cell disease- Issues of personal and sexual identity”, Vol. 10. No.6, USA, Saunders, 1996

Lagos State Government “Lagos Demography”, Lagos, 2006, accessed January 15th 2009, available under http://www.lagosstate.gov.ng/c/portal/layout?p_l_id=PUB.1095.7

Medline plus, medical encyclopedia, ”Sickle cell anemia”, Bethesda, 2009, accessed November 16th 2008, available under http://www.nlm.nih.gov/medlineplus/ency/article/000527.htm

MSN Encarta, “Geographic Distribution of the Sickle-Cell Mutation”, Microsoft cooperation, 2008, accessed January 5th 2009, available under http://encarta.msn.com/encnet/refpages/RefMedia.aspx?refid=461573602

National heart lung and blood institute, ”Blood diseases- Thalassemias”, Bethesda, USA, 2008a accessed February 2nd 2009, available under http://www.nhlbi.nih.gov/health/dci/Diseases/Thalassemia/Thalassemia_WhatIs.html

National heart lung and blood institute, ”Blood diseases- Sickle cell Anaemia”, Bethesda, USA, 2008b, accessed February 2nd 2009, available under http://www.nhlbi.nih.gov/health/dci/Diseases/Sca/SCA_SignsAndSymptoms.html

Natural Sciences Learning Centre (NSLC), “Discovery and biological basis- sickle cell”, Washington, 2003, accessed February 16th 2009, available under http://www.nslc.wustl.edu/sicklecell/part1/background.html

Ogbe, H., “Sickle cell- how to cope” spectrum books, Ibadan, Nigeria, 2004

Sickle Cell Foundation Nigeria, “Sickle cell anemia, the facts”, Lagos, Nigeria, 2008a

Sickle Cell Foundation Nigeria, “Living Healthy with Sickle Cell Anemia” Lagos, Nigeria, 2008

Sickle Cell Foundation Nigeria, “About sickle cell”, Lagos, Nigeria, accessed November 6th 2008, available under http://www.sicklecellfoundation.com/sicklecell.asp

Sickle Cell Society London, “Inheritance of sickle cell anemia”, London, 2004, accessed November 3rd 2008, available under http://www.sicklecellsociety.org/education/inherit.htm

Sickle cell disease association of America, Inc. (SCDAA), “Sickle cell disease”, accessed December 27th 2009, available under http://www.sicklecelldisease.org/about_scd/index.phtml

Sickle cell information centre Georgia, ”Sickle cell disease- FAQ”, Georgia, 2004a, accessed January 15th 2009, available under http://www.scinfo.org/faqdisease.htm

Sickle cell information centre Georgia, ”Sickle cell trait”, Georgia, 2004b accessed January 15th 2009, available under http://www.scinfo.org/sickletrait.htm

The Internet Journal of Hematology, “Sickle Cell Disease- History and origin”, Volume 1 no. 2, 2004, accessed November 16th 2008, available under http://www.ispub.com/ostia/index.php?xmlFilePath=journals/ijhe/vol1n2/sickle.xml

U.S. Department of State, ”Nigerian international religious freedom report”, Washington, 2003, accessed February 15th 2009, available under http://www.state.gov/g/drl/rls/irf/2003/23745.htm

UK new born screening programme centre “why are new born babies screened for sickle cell disorders in the UK?”, UK, 2005, accessed January 14th 2009, available under http://www.newbornbloodspot.screening.nhs.uk/download/infosheet_SCD.pdf

United Nations Economic Commission for Africa (UNECA), “Book of abstracts- science with Africa conference”, Addis Ababa, 2008, p.30, accessed January 23rd 2009, available under http://www.uneca.org/sciencewithafrica/content/swa_book_of_abstacts-en.pdf

University of Maryland medical centre, “Blood diseases- sickle cell disease”, Maryland, 2008, accessed February 2nd 2009, available under http://www.umm.edu/blood/sickle.htm

World Bank, “Nigeria-country brief”, Washington, 2008, accessed January 15th 2009, available under http://web.worldbank.org/WBSITE/EXTERNAL/COUNTRIES/AFRICAEXT/NIGERIAEXTN/0,,menuPK:368906~pagePK:141132~piPK:141107~theSitePK:368896,00.html

World Bank, “HIV/AIDS in Africa- Nigeria”, Washington, 2007, accessed February 15th 2009, available under http://web.worldbank.org/WBSITE/EXTERNAL/COUNTRIES/AFRICAEXT/EXTAFRHEANUTPOP/EXTAFRREGTOPHIVAIDS/0,,contentMDK:20450497~pagePK:34004173~piPK:34003707~theSitePK:717148,00.html

World Health organization (WHO), “Sickle cell Anemia”, fifty-ninth world health assembly (A59/9), WHO, Geneva, 2006a, accessed November 3rd 2008, available under http://www.who.int/gb/ebwha/pdf_files/WHA59/A59_9-en.pdf

World Health Organisation (WHO), “Fifty sixth session- Sickle cell disease in the African region”, executive summary, Regional committee for Africa, Addis Ababa, 2006b, accessed November 3rd 2008, available under http://afrolib.afro.who.int/RC/RC%2056/Doc_En/AFR-RC56-17%20Sickle%20Cell%20Disease%20-%20Final.pdf

World Health Organization (WHO),”WHO country co-operation strategy Nigeria”, WHO, Regional office for Africa, Brazzaville, 2005, accessed February 17th 2009, available under http://www.who.int/countryfocus/cooperation_strategy/ccs_nga_en.pdf

World Health Organization (WHO), “Health systems improving performance- Nigeria” World Heath Report, 2000, p. 154, accessed February 17th 2009, available under http://www.who.int/whr/2000/en/whr00_en.pdf

Statutory Declaration

I declare that I prepared and wrote this paper entirely by myself, without any external help and only using the sources mentioned. This thesis - or any variation there of - has never been submitted to any other examination authority.

Hamburg,

Elele Ejodame

Annex

1. The questionnaire

Elele Ejodame
Health Sciences
University of Applied Sciences Hamburg, Germany

Questionnaire for qualitative expert interviews

Sickle Cell Disease as a major public health concern in Nigeria

Date…… Duration…… Interview Nr……..

Demographics

- Age (years)
  20 – 30 ( ) 31 – 40 ( ) 41 – 50 ( ) 51 – 60 ( ) 60 – 70 ( )
- Male ( ) / Female ( )
- Profession? How long have you been in this field of work?
- In which state is your place of work?

Public Health and prevention

1. When you think of sickle cell disease in Nigeria, what is the first thing that comes to your mind spontaneously?

2. Do you think sickle cell disease is a public health issue in Nigeria? If so why?
   a. What are the consequences?

3. What is your view on the stand of the Nigerian Health System in the fight against sickle cell disease?
   a. What problems / limits do you think could arise in developing an efficient intervention scheme for Sickle cell disease in Nigeria?
   b. Do you know of any governmental programmes or co-operations for sickle cell disease in Nigeria? Which…?

i. How do you find the quality of these programmes?
ii. Is there any room for improvement?

4. Do you know of any NGO programmes for sickle cell disease in Nigeria? Which..?
    a. Do you know any of their projects?
        i. How do you find the quality of these programmes?
        ii. Is there any room for improvement?

(Question particularly for Experts from Sickle cell organization)

    b. When planning a new project or intervention scheme, are there any guidelines or recommendations or existing concepts from other countries you or your organization follow(s)?
    c. Does your organization have cooperating partners in other country's or in other world-, or African organizations?

5. What are realistic goals which can be achieved with an optimal sickle cell disease awareness and prevention scheme?
    a. If you had the resources to change anything and improve the present situation of sickle cell disease in the country, what would you change?
    b. What institutions would you personally see as good mediums to support awareness and prevention schemes (Governmental or NGO).

Sickle Cell Disease and important factors

6. How would you describe the situation of sickle cell affected individuals?
    a. Health wise
    b. Socially

7. In your opinion, what factors reduce the life expectancy and quality of life of sickle cell affected in Nigeria? Compared to some developed countries where sickle cell affected have higher life expectancies and a better quality of life.
    a. Many patients with sickle cell disease take pain killers regularly. These have negative aspects and could lead to an addiction.
    What do you think about this?

8. What of sickle cell carriers? How do you see their situation?
    a. Health wise
    b. Socially

9. What is your view on genetic counselling for engaged or expecting couples?

10. What do you think is the most important aspect to be considered in the prevention of sickle cell disease in a country like Nigeria?

11. Considering all what you have said how do you see / estimate the situation in the future? Let us say the next 7 years.

12. Is there anything else you would like to say or contribute?

Thank you very much for your kind participation!

2. The categories

Categories for the qualitative Interviews

Category 1

Sickle cell disease in Nigeria, influencing factors and consequences

(Questions 1 and 2)

Category 2

Health services and organizations for sickle cell disease

(Questions 3 and 4)

Category 3

Public health and intervention

(Questions 5 and 9)

Category 4

The individual and influencing factors typical for Nigeria

(Questions 6, 7 and 8)

Category 5

Future prospects

(Questions 10 and 11)

Category 6

Others

(Question 12)


5°E
10°E
NIGER
CHAD
SOKOTO
Sokoto
Katsina
KATSINA
JIGAWA
Kano
YOBE
BORNO
Lake Chad
Maiduguri
ZAMFARA
KANO
KEBBI
Zaria
KADUNA
Kaduna
BAUCHI
GOMBE
Kumo
BENIN
10°N
NIGER
Joa
NIGERIA
ADAMAWA
Yola
Niger
Abuja
PLATEAU
KWARA
ABUJA F.C.T.
Ilorin
OYO
Ogbomosho
Oyo
NASSARAWA
TARABA
Benue
Oshogbo
EKITI
OSUN
KOGI
Makurdi
Ibadan
BENUE
Abeokuta
Ondo
ONDO
OGUN
EDO
ENUGU
Benin City
Enugu
EBONY
LAGOS
Onitsha
ANAMBRA
Lagos
Sapele
CROSS-RIVERS
CAMEROON
DELTA
IMO
ABIA
5°N
Aba
Uyo
Calabar
Gulf of Guinea
RIVERS
BAYELSA
Port Harcourt
AKWAIBOM
0
100 miles
0
100 kilometres
5°E
10°E
©Oxford Cartographers

Table of contents

Acknowledgements

A very special thank you goes to all the people I interviewed in Nigeria for being so helpful, open and welcoming. Very many people contributed to this project by graciously spending the time to be interviewed and sharing their ideas with me. Without your valuable contributions and information, this project would not be.

I also covey my deep gratitude to the persons I interviewed who are affected with sickle cell disease. Thank you for sharing your experiences with me.

In particular, I would like to thank the coordinator of the Sickle Cell Foundation in Lagos for referring me to so many valuable contacts. I am especially grateful to Dr. Onaiwu who is the medical director of the Sickle Cell Centre in Benin City, Professor Akinyanju the chairman of the Sickle Cell Foundation in Lagos and Dr. Ihongbe who is the Head of Department of the College of Medicine at the Ambrose All University in Ekpoma. Thank you all for your energetic involvement and valuable input to this project.

I would also like to express my appreciation to my supervisors at the University, Professor. Dr. Dr. med. Karl- Heinz Wehkamp and Professor. Dr. Gabrielle Perger, thank you for your excellent supervision, guidance and friendly support through out this project.

I am especially grateful to my family. Thank you for your inspiration, support and encouragement in every way.

And lastly, I would like to thank God.

Thank you all for contributing to this project.

Figures and Tables

Figures:

Tables:

Abbreviations

CDC	Centre of Disease Control
Hb	Hemoglobin
HIV	Human Immunodeficiency Virus
Lab	Laboratory
IFAD	International Fund for Agricultural Development
NGO	Non Governmental organization
NAFDAC	National Agency for Food and Drug Administration and Control
NAPCA	National Action for Prevention and Control of AIDS
NPHCDA	National Primary Health Care Development Agency
NIMR	Nigerian Institute for Medical Research
NPI	National Programme on Immunization
SCD	Sickle Cell Disease
UNECA	United Nations Economic Commission for Arica
WHO	World Health Organization