

# African Research Review

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An International Multidisciplinary Journal, Ethiopia

Vol. 8 (2), Serial No. 33, April, 2014:1-18

ISSN 1994-9057 (Print)

ISSN 2070--0083 (Online)

DOI: <http://dx.doi.org/10.4314/afrev.v8i2.1>

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## **The Role of Social Welfare Counselling in the Eradication of Sickle-Cell Disease in Nigeria Beyond 2025**

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### **Abstract**

*Sickle-Cell anaemia is a genetic blood disorder that has no cure presently, but it could be eradicated. It is a common disease among the blacks; hence, it is necessary to look into the strategies in eradicating this deadly disease. It is found that the disease has no cure yet, but kills people in their thousands. It is as deadly as HIV/AIDS. The percentage of the carrier is on the high side, and as such the carriers will continue to increase in number on daily basis if not controlled. Hence, social welfare counselling and other techniques can help in educating carriers towards the prevention and eradication of this deadly disease. Therefore, efforts have to be urgently put in top gear to salvage the lives of the able black race. This discourse will be a useful guide to individuals who are already or about to be engaged, and also for counselling in social, religious, health and educational sectors. It is also useful at the Local Government Level, State Government and the Nation at large, if the*

*procedure in combating sickle cell anaemia is taken into consideration.*

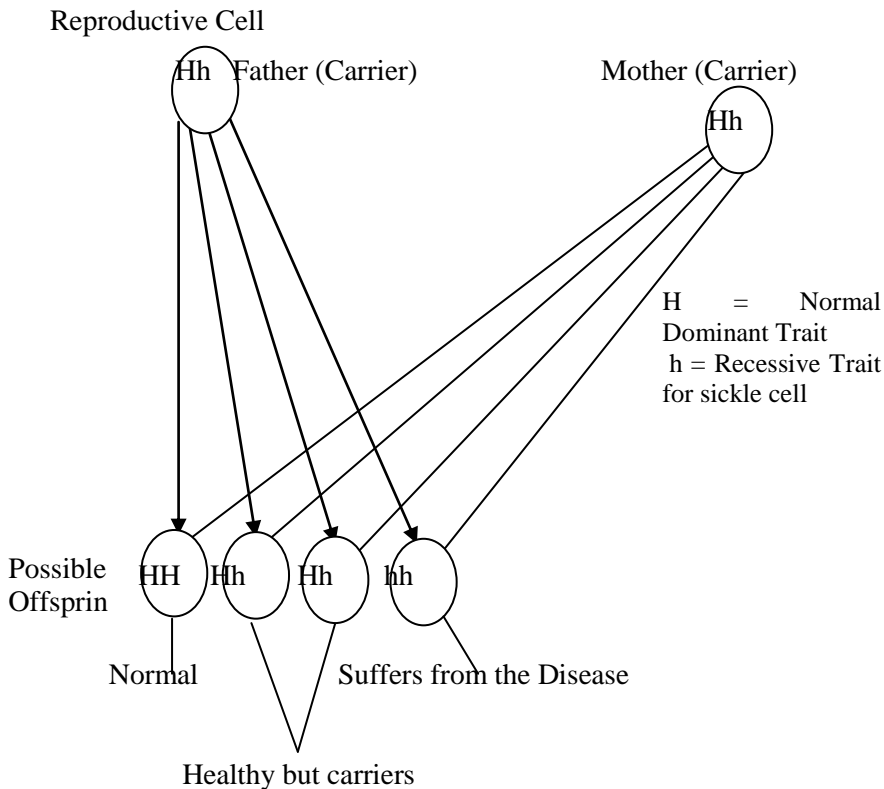
**Key Words:** Sickle-Cell Anaemia Disease, Strategies, Eradicating

## **Introduction**

Midence and Elander (1994) asserted that Sickle cell is a disorder of the blood. Part of the blood are the red cells because the blood contains plasma, which is the fluid with, tiny particles that are invisible to the naked eyes, but are actually living cells. Red blood cells, the white blood cells and the platelets are millions in the blood. Inside this red blood cell are substances called haemoglobin which carry oxygen from lungs to the different parts of the body. Because the blood circulates, this oxygen is eventually carried to the body and is released to make them function. In the affected individuals, the red blood cells are sickle, that is, they take on distorted shapes and become rigid. When sickle red corpuscles become wedged in the capillaries, blocking local blood flow, the sickle cell haemoglobin molecules occur, forming pseudo crystalline structures known as tactoids; this process is known as sickling.

The sickle cell disorder is hereditary, not infectious. The disease has been traced to a single recessive gene. Because the gene is recessive, it must have been inherited from both parents for a child to develop the disease (Alawale, 1998). Any child with one sickle cell gene and one normal gene in his or her genetic makeup is completely healthy, but he or she is a carrier; that is she/he carries the sickle cell trait, and capable of passing the trait on to his/her offspring. If a sickle cell carrier marries someone who also has the sickle cell gene, some of their children may develop the disease and some of them may not. The chances of children inheriting sickle cell disease where both parents are carriers can be illustrated by the diagram below.

## Hereditary possibilities of transmitting sickle cell diseases



**Source:** Alawale, (1998)

Counselling and prevention of causes and infections are simple measures not readily accessible to most patients. As a result, the majority of children with the most severe form of the disease die before the age of five, usually from an infection or severe anaemia. The survivors remain vulnerable to exacerbations of the disease and the complications mentioned above.

SCD has major social and economic implications for the affected child as well as the family. Recurrent sickle-cell crises interfere with the patient's life, especially with regard to education, work and psychosocial development.

Presently, there is no cure for SCD. However, cost-effective treatment exists for the pain and other aspects of the disease. The most important components of this treatment are early intervention with analgesics, antibiotics, rest, good nutrition, folic acid supplementation and high fluid intake. At times, invasive procedures such as blood transfusions and surgery may be needed.

### **Epidemiology of sickle cell disease**

SCD is present mostly in blacks. It is also found, with much less frequency, in eastern Mediterranean and Middle East populations. Individuals of Central African Republic descent are at an increased risk of overt renal failure. The sickle gene is present in approximately 8% of black Americans. The expected prevalence of sickle cell anaemia in the United States is 1 in 625 persons at birth. The actual prevalence is less because of early mortality. More than 2 million people in the United States, nearly all of them of African American ancestry, carry the sickle gene.

According to National Institutes of Health and Centres for Diseases Control and Prevention; the following statistics are available:

- Sickle cell anaemia is the most common inherited blood disorder in the United States.
- More than 70,000 people in the United States have sickle cell disease.
- Sickle cell disease occurs in 1 in every 500 African Americans.
- About 8% of African Americans are carriers of sickle cell disease.
- Two million people have sickle cell trait.
- Approximately 1 in 12 African Americans has sickle cell trait.

In the United States, SCD accounts for less than 1% of all new cases of end-stage renal disease (ESRD) (Abbott, Hypolite, Agodoa, 2002). The following factors are known to portend a greater likelihood of progression to overt renal failure; hypertension, nephritic-range protein-uria, severe anaemia, and a Central African Republic heritage (Derebail, Nachman, Key, Ansele, Falk, Kshirsagar, 2010). In patients with SCD, 5 – 10% developed renal failure (Scheinman, 1994).

In 2006, the World Health Organization (WHO) pronounced Nigeria as the country with the highest number of sufferers of sickle cell anaemia in the world. The global health watch along put the annual number of sickle cell anaemia sufferers in Africa at about 200,000, noting that Nigeria account for 150,000 sickle cell anaemia children every year (Sheyin, 2012).

In Nigeria, there is no accurate account since the majority born to rural dwellers does not survive childhood (Ukpong, 1992). He ascertained in the research that about 9000 births would have sickle cell disorder by the end of that year. However between 1992 and till date, the number has greatly increased because of multiplication effects and due to Nigerians flair for children. Unfortunately, the issue of Malaria has complicated and worsens the issue. Most people with normal blood genotype – AA, die prematurely due to severe illness caused by malaria. Infants and children are vulnerable because they would have had fever infections and could not build up immunity against the parasite. Hence, the available AS genotype inter-marry which makes majority become carrier of SCD; the carriers would then increase in number making the control more difficult.

However, recent medical findings (Centres for Disease Control and Prevention, 2007) show that about 30 percent of Nigerians are carriers of the mutant gene, with the prevalence rate at 20 per 1,000 births. “With the carrier frequency ranging between 20 percent and 30 percent of Nigerians population, it means that more than 30 million Nigerians are carriers” the report stated. The disease, according to

medical sciences is inherited from both parents and is usually caused by some abnormalities in a type of haemoglobin called haemoglobin-s. Symptoms of the disease vary, but a research conducted by Adeyokunnu and Hendricks in Sheyin (2012) both of the University College Hospital, Ibadan, shows the sufferers have pain episodes, usually referred to as crisis which can last between hours and days. They asserted in their research that some carriers suffer abdominal pain, breathlessness, delayed growth and puberty, fatigue, fever, ulcers, among others.

Senator Gyang Dantog, Chairman, Senate Committee on Health, notes that sickle cell anaemia has been proved to be more fatal than HIV/AIDS. He describes the effects of the disease as very devastating and declared that Nigeria could not afford to remain its “World Capital”. Dr Artemos Francis, a Kaduna-based medical practitioner, believes that the first step toward checking the menace is to prevent the occurrence. He asserted that sickle cell can only occur when two people, who carry the sickle cell trait, have a child together. Hence, it is necessary to intensify counselling intending couples to go for tests to determine their status.

The federal government of Nigeria showed concern in the struggle to abate the burden sickle cell patients do experience. In his speech while commissioning the Multi-million Naira Ultra-Modern National Sickle Cell Centre, opposite Lagos University Teaching Hospital (LUTH), Idiaraba Lagos, the then President, Olusegun Obasanjo expressed his worry over the sickle cell anaemia incidence in Nigeria and asked the Committee to advise the Federal Government on what to do to reduce the scourge of the disease in the country. In his address the Chairman of the foundation, Professor Olu Akinyanju (2007) disclose that, Nigeria by her large population harbours the highest number of sickle cell patients in black Africa, with 150,000 new patients yearly and 40 million people with the traits of the disease.

### **Complications and problems associated with sickle cell disease**

According to University of Maryland, Medical Centre (2013), there is still no cure for sickle cell disease other than experiment transplantation procedures but treatments for complications of sickle cell have prolonged the lives of many patients who are now living into adulthood. The hallmark of sickle cell diseases is the sickle cell crisis which is an episode of pain. It is the most common reason for hospitalization in sickle cell disease. In general, the risk for a sickle cell crisis is increased by any activity that boosts the body's requirement for oxygen such as illness, physical stress or being at high altitudes. In more than half of episodes, however, the trigger is unknown. Episodes typically begin at night and last 3 – 14 days, accelerating to a peak over several days and then declining. Pain most commonly occurs in the lower back, leg, hip, abdomen or chest, usually in two or many locations. Pains in the bones are common because blood obstruction can directly damage bone and because bone marrow is where red blood cells are manufactured.

Acute Chest Syndrome (ACS) occurs when the lung tissues are deprived of oxygen during a crisis. It can be very painful, dangerous and even life threatening. It is a leading cause of illness among patients with sickle cell disease and is the most common condition at the time of death. The pain often lasts for several days. In about half of patients, severe pain develops about 2 – 3 days before there are any signs of lung or chest abnormalities. Acute Chest Syndrome is often accompanied by infections in the lungs, which can be caused by viruses, bacteria or fungi. Pneumonia is often present.

Infections are common and an important cause of severe complications. Before early screening for sickle cell disease and the use of preventive antibiotics in children, 35% of infants with sickle cell died from infections. Fortunately with screening tests for sickle cell now required for newborns, and with the use of preventive antibiotics and immunizations in babies who are born with the disease, the mortality rate has dropped significantly. Such infections pose a

serious threat to infants and very young children with sickle cell disease. They can progress to fatal pneumonia with devastating speed in infants, and death can occur only a few hours after onset of fever. Infections are also common in older children and adults with sickle cell disease, particularly respiratory infections such as pneumonia, kidney infections and osteomyelitis, a serious infection in the bone.

About 30% of patients with sickle cell permanent partial or complete erectile dysfunction can occur. Enlargement of the liver occurs in over half of sickle cell patients and acute liver damage occurs in up to 10% of hospitalized patients. Because sickle cell patients often need transfusions, they are at higher risk for viral hepatitis, an infection of the liver. This risk, however, has decreased since screening procedures for donated blood have been implemented.

Gallbladder disease is common among sickle cell patients. About 30% of children with sickle cell disease have gallstones, and by age 30, 70% of patients have them. In most cases gallstones do not cause symptoms for years. When symptoms develop patients may feel overly full after meals, have pain in the upper right quadrant of the abdomen, or have nausea and vomiting. Acute attacks can be confused with a sickle cell crisis in the liver. Ultrasound is usually used to confirm a diagnosis of gallstones. If the patient does not have symptoms, no treatment is usually necessary.

In some children with SCD, excessive production of blood cells in the bone marrow causes bones to grow abnormally, resulting in long legs and arms or misshapen skulls. Sickling that blocks oxygen to the bone can also cause bone loss and pain. Sickling that affects the hands and feet of children causes a painful condition called hand foot syndrome. A condition called avascular necrosis of the hip occurs in about half of adult sickle cell patients when oxygen deprivation causes tissue death in the bone. Eventually adult patients may need surgery to remove diseased and dead bone tissue. Patients with severe causes may need joint replacement.



Leg sores and ulcers may occur in the sufferers of SCD. They usually affect patients older than 10 years. SCD can also damage blood vessels in the eye and cause scarring and detachment of the retina, which can lead to blindness. Women with SCD who become pregnant are at higher risk for complications such as miscarriage and premature birth, and their babies may have low birth weight. SCD symptoms often worse during pregnancy and pain crises become more frequent. However with careful prenatal care and monitoring, serious problems can be avoided. Older children and adult patients with SCD are subject to other medical problems, disease have pulmonary hypertension.

Stroke is the second most common killer of patients with sickle cell disease who are older than 3 years old. Between 8 – 10% of patients suffer strokes, typically at about age 7. Strokes are usually caused by blockages of vessels carrying oxygen to the brain. Patients with sickle cell disease are also at high risk for strokes accused by aneurysm, a weakened blood vessel wall that can rupture and haemorrhage. Multiple aneurysms are common in sickle patients but they are often located where they cannot be treated surgically.

Anaemia is a significant characteristic in sickle cell disease commonly referred to as sickle cell anaemia. Because of the short lifespan of the sickle red blood cells, the body is unable to replace red blood cells as quickly as they are destroyed. This causes a particular form of anaemia called haemolytic anaemia. Most patients with sickle cell disease have haemoglobin levels of about 8gldL, much lower than healthy people. Chronic anaemia reduces oxygen levels and increases the demand on the heart to pump more oxygen bearing blood through the body. Eventually, this can cause the heart to become dangerously enlarged, with an increased risk for heart attack and heart failure.

The kidneys are particularly susceptible to damage from the sickling process. Persistent injury can cause a number of kidney disorders, including infection. Problems with urination are very common, particularly uncontrolled urination during sleep. Patients may have

blood in the urine, although this is usually mild and painless and resolves without damaging consequences. Kidney failure is a major danger in older patients and accounts for 10 – 15% of deaths in sickle cell patients. About 40% males, including children with SCD suffer from priapism. Priapism causes prolonged and painful erections that can last from several hours to days.

There was a caption, ‘pain, pain and pain’ in the widely read News Paper, ‘Sunday Punch’ of 24th September 2006. This was an expression of some Nigerians, parents of sickle cell disease patients who met and lamented on the agony they go through and the discrimination that goes with it. In a rare display of emotions, many of them narrated the pain they have had to suffer for harbouring a dysfunctional genotype. Some of the women who spoke with *Sunday Punch* however claimed that they were not ignorant of the disease, but were victims of wrong and faulty laboratory diagnosis.

### **Symptoms of sickle cell disease**

Sickle cell disease is usually diagnosed during childhood. However, some milder form of the disease can be missed if certain blood tests are not complete. One should be concerned about having sickle cell disease if one has:

- i. Unexplained pain in abdomen, chest, back, joints and muscles fatigue.
- ii. Anaemia that does not respond to iron supplements.
- iii. Family history of sickle cell disease or sickle cell trait.
- iv. Medical Laboratory Test.

If one has been diagnosed with sickle cell disease, one can decrease the frequency of pain crisis by following some simple guidance.

- i. Maintain good nutrition, including supplement of folic, zinc and vitamin E.
- ii. Drink plenty of fluids, especially during hot weather, exercise or when travelling.
- iii. Plain water and fruit juices are best choices.

- iv. Use over the counter medication, warm baths, heating pads, fluids and bed rest at the first indication on onset of a pain episode.
- v. Use of acupuncture, between feedback and relaxation to reduce the stress of the disease.

Another treatment given to sickle cell anaemia patients is Bone Marrow Transplanting (BMT). It is being reported with increasing frequency but remain controversial in spite of encouraging results. The type of BMT done for sickle cell anaemia patients is Alogenic Bone Marrow Transplantation. The concern raised by opponents to this treatment for sickle cell anaemia are the acute and long term complications, morbidity, and costs compared with traditional therapy of disease

Mirabel tea is also used to boost Haemoglobin levels among people who have anaemic conditions such as SCD. Mirabel tea has tremendous anti-sickling properties. Regular consumption of Mirabel tea has been associated with the prevention of the crisis and pain in people living with SCD.

There is also a control measure, which is the termination of early pregnancy. The foetus is tested at the embryonic stage, and if found to be a carrier, the pregnancy is terminated at the early stage before three months. However, the woman is subjected to carrying many pregnancies in which only few that are tested to be non-carriers will be allowed to live. As a matter of fact, this is also expensive and it can endanger the life of the woman in question. The best option to embark on is total eradication.

### **Implication for social welfare counselling/ solution and recommendations**

Counselling and prevention of causes and infections are simple measures not readily accessible to most patients. As a result, the majority of children with the most severe form of the disease die before the age of five, usually from an infection or severe anaemia.

The survivors remain vulnerable to exacerbations of the disease and the complications mentioned above. SCD has major social and economic implications for the affected child as well as the family. Recurrent sickle-cell crises interfere with the patient's life, especially with regard to education, work and psychosocial development.

The prevention and control is indeed what can eradicate and combat the disease in this century. Unfortunately, the area of sickle cell disease has been known many decades ago, but people don't seem to show interest in the eradication. It has drained the purses of many and destroyed many homes and yet people show nonchalant attitude about it. Hundreds and thousands are dying daily due to this incurable disease. It is right time to educate and create awareness for people to know about sickle cell disease and avoid it like a plague, just as people avoid HIV/AIDS today.

All newly born babies should be tested for sickle cell disease, because all forms of sickle cell disease are inherited. The test should be done in recognized and well-equipped medical laboratories or any health institutions. Children inherit the genes for the disease from their parent, hence there is need to encourage everyone to know more about it.

Eradication of sickle cell disease now depends on the awareness of the disease and guide against the elongation by the masses. The awareness should be done in various organizations such as religious, social, health and academic sectors of our society. Specifically, SCD can be eradicated through the following measures.

### **Public education**

Accurate, current and clearly written information about sickle cell disease should be produced and made widely available in a credible form, to people. Different forms of communication can be used such as mass media, newspapers, magazines, flier, seminars and workshops in schools, hospitals, organizations, among others. Parents should be educated to educate their wards to know the danger inherent in having

children that are sickle cell disease carriers. They should advise their wards not to allow love to blindfold them into future problems, whereby they will not be able to enjoy their marriage as a result of offsprings that will make go in and out of the hospital. Parents can cite examples and educate their children with vivid experiences of people involved in this type of problems. The public awareness should start from the grass root, involving the N.G.Os and local government. There are three things that are extremely hard, steel, diamond and knowing one self. Public self consciousness has good effect on people. As with situationally induced public self-awareness, persons who are high in public self-consciousness tend to be more concerned about how others judge them (Fenigstein & Venable, 1992) and are more likely to withdraw from embarrassing situations than those low in this trait (Yoshitake, 1990). The tendency to comply with external standards encompasses physical appearance as well. A number of studies have found out that individuals high in public self-consciousness are more concerned about their physical appearance and believe appearance is important for smooth societal interaction (Striegel-Moore, Silberstein, Rodin 1993).

There should be outpatient clinic which should provide a setting for patients to be seen by a physician specializing in sickle cell disease. Clinic care should include the services of nurses and certified counsellors as well as a social service assessment. Recommendations for care to be coordinated with the patient primary care physician. And follow up visit should be scheduled for medical management and pain control.

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

Nevertheless, the dissemination of information can be made in a very simple language that people will understand the concept of sickle cell disease. They can be informed in this manner:

What is sickle cell disease? It is a genetic disorder that results in abnormally shaped red cells. It is inherited from the genes of the parents that are carriers. These distorted cells live only 10 – 20 days, compared to normal red blood cells which live about 120 days. This chronic undersupply of red blood cells makes the sickle cell patient anaemic. When the cells clump together, they cause blockages leading to a very severe pain, tissue and organ damage.

The above assertion can be meaningful to the individuals. They should also be intimated with its economic waste, the life of the individual involved is under jeopardy coupled with daily stress.

### **Transition programme**

To expel this problem from our society, the system of catching them young can be adopted. This is better done at the beginning of late childhood, which is usually the beginning of secondary school education in many societies. To make the awareness rooted, it can be inculcated in the curriculum of the secondary school students especially in their biology subject, but the area of sickle cell disease should be emphasized. They should also be made to understand the implication of the disease in daily living. The awareness should be thorough at the tertiary level because it is actually from this stage many of the youngsters meet their spouse. Proper counselling is very necessary at this stage.

### **Premarital counselling**

Marriage institution is the bedrock of every society. Premarital counselling is the type of counselling given to youths or couple-to-be

to guide against what can erupt in marital life which can lead to endured marriage and even divorce as the case may be. Among many things that can lead to marriage breakdown is health issue. If the marriage is producing unhealthy children, peace and joy that a marriage is meant to witness will be evaded (Olayinka, 2000).

Premarital counselling is better given early enough before the two love birds get so enlarged, becoming inseparable as they usually perceive it. Parents should also be bold enough to take their wards for premarital counselling before it is too late. The Counsellor will discuss so many issues in which blood compatibility in terms of genotype can be expatiated. This is a serious issue that the parents should not handle it with levity. It is better for the parents of the two to take their wards for the test themselves in order to avoid deceit. There are also some clergy that are trained Counsellors who should be ready to use their expertise to save mankind. The truth would have to be said whether sweet or bitter if the couple-to-be have AS as their genotype, they should be made to understand the repercussion, the high probability of having children with sickle cell disease and the associated problems, with the pains they are likely to encounter in the area of rearing children. Many of our youths are love intoxicated. The advice may not be meaningful to them, but the experiences of other people that have suffered such menace can be shared with them.

### **Speakers' bureau**

Sickle cell disease patients can come together forming a body. The organization can choose a specific month for their annual meeting, just like the Breast Cancer Awareness (BCA), Prostate Cancer, Cervical Cancer, HIV/AIDS, to mention a few among others. There should be sickle cell programme in some of our medical centres to provide a variety of services to assist patients and their families in understanding and living with this genetic disorder. In this forum, specialized physicians can educate them on coping strategies and more importantly equipped with first hand information to enlighten the masses on prevention of the disease. This forum should not

encourage self-pity or sympathy but frank talk that would help the victims to cope and also discourage others falling victims. This kind of seminar should be given wide publicity and making it lively but ensuring that it passes across the information it is expected to pass to the masses. Clubs, individuals, religious organization, both educational and health sectors can be called upon for moral and financial support.

In conclusion, sickle cell disease is not infections or contagious, but with all seriousness, it can be eliminated. Taking the above steps into serious consideration, Nigeria can be in the forefront among black nations to fight and eradicate the deadly disease. The sickle-cell disease which has been on rampage for many centuries in Arica can be curbed in Nigeria within the next decade in this millennium.

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