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Sickle Cell Disease (SCD) Mortality Is Preventable Through Evidence-Based Interventions and Other Measures - Prof. Obiageli Nnodu

Prof. Nnodu is the Special Adviser to the Nigerian Coordinating Minister of Health and Social Welfare, on SCD.

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Publisher's Note

Management of SCD is focused on preventing and treating pain episodes and other complications. Prevention strategies include lifestyle behaviors as well as medical screening and interventions to prevent SCD complications. A common hereditary disease, it can be prevented by preparing young persons ahead of the conception of an affected foetus. The disease is an autosomal-recessive genetically transmitted haemoglobinopathy that is responsible for considerable morbidity and mortality.

Normal red blood cells are round flexible disks. They slide through the blood vessels, carrying oxygen to the organs and tissues. Sickled cells are stiff and sticky and get stuck in the blood vessels, instead of flowing throughout the body. Complications of sickle cell anemia can be life-threatening. In the past, babies born with this condition rarely lived to be adults. Now, thanks to early detection and new treatments, more persons live longer. Have a pleasant reading.

Olaedo Nelson.

Sickle Cell Disease (SCD) Mortality Is Preventable Through Evidence-Based Interventions and Other Measures - Professor Obiageli Nnodu

SCD (SCD) is the inheritance of at least one abnormal gene for sickle haemoglobin from each parent. Major sickle genotypes include sickle cell anaemia which is homozygous sickle haemoglobin ie HbSS and the most common form. Other types include heterozygous forms with HbS and another abnormal haemoglobin such Haemoglobin C (HbSC) or Hb Hereditary persistance of faetal globin (HbS/HbHPFH). These usually clinical less severe phenotypes.

Can this disease be avoided?

According to Professor Obiageli Nnodu, Director, Centre of Excellence for SCD, Research and Training, University of Abuja, SCD could be prevented if carriers of the sickle haemoglobin refrain from marrying each other. The awareness prior to when an individual gets married is important to the prevention of SCD. The severity of SCD can be reduced through the application of evidence-based interventions.

In this interview Professor Nnodu had with Mediaage, she shed more light on major things the society needs to know of SCD. Excerpts:

Can you introduce yourself to our readers?

My name is Professor Obiageli Nnodu. I'm a Consultant Haematologist and Professor of Haematology and Blood Transfusion. I'm the Director of the Centre for Excellence in SCD Research and Training at the University of Abuja. I'm also the Chairperson of the Sickle Cell Support Society of Nigeria, which is an NGO representing the interests of patients, parents, professionals, and other NGOs involved with SCD in Nigeria and the diaspora. The Sickle Cell Support Society was established in 2010, incorporated in 2014, and has representatives in the six geopolitical zones of the country.

Thank you for that brief introduction. Is it true that individual management of SCD is not affordable for majority of Nigerians who live with the condition?

This statement is not accurate at all because, the most important aspect of managing SCD is early diagnosis, which is very affordable through cost-effective methods. Early diagnosis, followed by education of parents or caregivers on simple evidence-based interventions, can actually impact the clinical course of the disease. It ensures that the baby or child grows into adulthood.

Such simple interventions include parental education about SCD, ensuring that the baby receives oral penicillin, folic acid, and the full complement of immunizations under the National Program for Immunization. The baby also starts taking hydroxyurea from nine months, which is a disease-modifying drug. The baby is screened and enters comprehensive care involving various healthcare workers such as pediatricians and adult hematologists, nephrologists, orthopaedic and plastic surgeons, cardiologists as the baby grows and transitions.

These professionals will monitor the different

target organ complications that could arise in the course of the illness. We refer to this as comprehensive care. Fundamental to this approach is education for the parents to understand how to maintain good health and prevent complications. This health education is very important, teaching parents how to provide optimum nutrition and hydration for the baby, how to avoid and treat infections properly, and how to recognize acute complications. Parents are taught to seek care immediately for harmful complications such as acute malaria, acute chest syndrome, and splenic sequestration. We teach mothers how to palpate the spleen on the left side of the abdomen, check if it is enlarged, and report immediately.

These are some of the measures that, when implemented as part of regular health maintenance, help children thrive. Particularly important is avoiding frequent mosquito bites to prevent malaria. You will find that babies receiving this care do well. However, the most crucial factor is hydration because dehydration can easily trigger a crisis. Other preventive measures include ensuring that the doors and windows of the house have nets, making sure they sleep under treated nets, and taking prophylaxis for malaria. These are some of the common practices they can adopt.

Because sickle cell patients have a high risk of stroke, we ensure they undergo screening. There is a test called Transcranial Doppler Ultrasound Scan that we introduce to children from age two up to age sixteen, and we conduct an annual check to assess their risk of stroke. If they are at high risk, we provide interventions through blood transfusions to reduce the level of hemoglobin S and through hydroxyurea treatment, which also modifies the disease by increasing the level of fetal hemoglobin.

As the child grows older, we begin to screen for chronic organ complications and damage, monitoring the heart and kidneys, for example. Sometimes, they may develop leg ulcers, and these are some of the conditions we watch for and provide care for during their visits.

Thank you for that very impressive response. The government in one of its press briefings last June said there is hope in the fight against SCD. Do you have an idea of the measures it is trying to put in place through the Ministry of Health?

In reality, the government has accomplished a considerable amount in terms of policies and establishing guidelines for management. When the government establishes these policies, it is the responsibility of stakeholders to ensure they are executed. Fundamental to this is the government's non-communicable disease policy, which has actually established multi-stakeholder engagement for the control of non-communicable diseases. The government aims for individuals to be identified early in life with SCDs through newborn screening, and this newborn screening would be conducted at the primary healthcare level.

The government also intends for individuals to receive care for SCD at the same primary healthcare level. This aligns with patients' preferences, as evidenced by our screening program present in 25 Primary Health Centres in the Federal Capital Territory. When we identify babies with SCD, we recommend they come to

the Teaching Hospital to be enrolled in comprehensive care. Some mothers express a preference to receive that care closer to where they live, at the Primary Health Care center.

The government has a policy of universal screening, potentially utilizing point-of-care technology. Point-of-care technologies are low-cost test kits that can detect SCD without requiring significant infrastructure investment. Right there in the Primary Health Center, a newborn can be tested to determine if it has SCD. The government has a policy that newborn screening would be based on such low-cost methods. Of course, the government also has larger reference laboratories where confirmatory testing can be conducted.

We have both policy and strategic implementation plans that support research and multi-stakeholder involvement. For instance, the Education Ministry and Health Ministry are providing information about SCD, with all these stakeholders working together to ensure that the management and control of SCD is applied in the policy. This is very important.

In August, there was going to be a launch of some policy documents that would be released regarding non-communicable diseases, as well as the strategic implementation plans. This would allow all stakeholders to see what needs to be done and begin to work with them, defending the motive to ensure they spread the information.

These are some of the actions the government has taken. The government is also enabling health awareness and public sensitization, educating people in different geo-political zones, starting with the South West where the prevalence of SCD is highest. They are beginning there to teach healthcare workers how to use point-of-care technologies to detect individuals with SCD, not only babies but individuals of all ages. These are some of the initiatives the government has undertaken, and I am confident that you, as members of the press, have the rest of the information.

During that press briefing, the Minister, represented by Dr. Chukuma Anyike said Nigeria stands out as the most sickel cell endemic country in Africa and globally, ahead of countries like India and the Democratic Republic of Congo. As an expert in this field, have you come up with solutions that can take the country off that position?

This is not a single-person endeavor. We have collaborated with the government over many years to develop policies focused on early detection and screening. However, the most crucial aspect, which we are not emphasizing sufficiently, is the risk factor for having SCD, which lies with those who are carriers. Recently, I heard someone referring to individuals with SCD as carriers. This is incorrect; the carriers are those who have the sickle cell trait. That is, they have one abnormal hemoglobin and one normal hemoglobin, specifically AS or AC. Individuals with AS or AC are the primary drivers of the disease if they marry each other because, in each pregnancy, there is a 1 in 4 chance (per pregnancy) of having a child with SCD.

This probability remains constant regardless of the outcome of past pregnancies. Consequently, in some families, you may find three or four children with SCD. The fundamental solution, if we want to reduce the prevalence of the disease, is education.

Firstly, many people do not know their status before getting married, or they may know their status but not understand the implications of having SCD. They may not comprehend the types of problems and complications associated with the disease, such as repeated illnesses, the impact on the family budget, the catastrophic health expenditures they may face, and the various complications that can arise. Imagine a child who is growing well, then suddenly starts experiencing repeated strokes that can be so

severe that they set the child back in terms of cognitive development. These children can grow into adulthood unable to care for themselves because SCD has damaged their brain. The consequences can be that severe. Alternatively, a child who is doing well may suddenly develop kidney problems or other chronic complications such as hip pain, immobility, or debilitating leg ulcers.

The frequent hospital visits, the emotional burden, physical limitations, and the overall impact on family life can be highly disruptive. Consider the current high cost of living, coupled with the unpredictability of pain crises and hospital admissions. When people are told that this disease is 100 percent preventable, they often do not fully grasp the implications. They may choose to act based on emotions rather than informed decision-making. What we need to do is educate people on how to avoid SCD in the first place. This is what we call primary prevention.

Failing that, and if people proceed to have children, the next step is to identify affected babies early. This has been one of our focus areas. In the past, we relied on expensive equipment, high levels of skill, and supply chains for consumables from abroad for newborn screening programs. However, these approaches have not been successful due to logistical challenges.

One of our recent achievements has been the application of point-of-care technology for newborn screening. While we did not develop this technology, when it became available, we evaluated its accuracy and sensitivity in detecting sickle cell carriers even in young infants. We were among the first globally to apply this technology to newborn screening.

We have provided the government with the opportunity to implement this point-of-care technology, and they have incorporated it into policy to identify affected individuals early. I believe that SCD prevalence is largely driven by ignorance, as people often do not fully understand its severity or how to maintain health with the condition. This is what we mean by comprehensive care. When we identify babies early and enroll them into care programs, they can do well.

They can grow optimally and thrive if evidence-based interventions are applied, including good nutrition, infection prevention, disease-modifying treatments, optimal hydration, and prompt management of acute complications through referral to higher centers. Many of these strategies can be taught to mothers. We have books and educational materials available. If you speak with sickle cell patients in their fifties, they often acknowledge that they came to understand their condition over time, learning what to avoid and how to take care of their bodies. This is the kind of understanding we need to promote.

It is essential that the public has access to this health information and education. Additionally, the schools where we train our healthcare workers should have a curriculum for the management of SCD, which is already in place, outlining best practices for care.

Moving beyond management, we also have curative treatments for SCD through bone marrow transplantation from a donor who does not have the sickle cell gene. With a perfectly matched transplant, the recipient can be cured, although genetically they still carry the sickle cell trait. However, their body no longer manifests the disease. We also have gene therapy as a curative option.

We need to prepare our Centers of Excellence and Teaching Hospitals to offer these curative treatments, as currently, many of our citizens are going abroad to access them. The first step is to establish enabling policies and legislation. Secondly, we need policies for screening and educating those who have the sickle cell trait. Our current policy mandates genotype testing at various stages of life: for kindergarten, primary school (during common entrance exams), secondary school (during JAMB), during National Youth Service Corps, and before marriage.

Each of these screenings should be followed by adequate education. You can see a comprehensive approach forming. Some countries have successfully implemented legislation to reduce the prevalence of SCD through education and genetic counseling. Genetic counseling services targeting those with the sickle cell trait are particularly important. We need to train more genetic counselors; currently, we have fewer than 500 in a country of over 240 million people.

We should discuss this issue at the population level to ensure the message reaches everyone. Our program encompasses primary prevention, early detection, application of evidence-based interventions, genetic counseling, education of healthcare workers, the use of standard guidelines for SCD management, and the incorporation of sickle cell education into healthcare curricula.

We also offer training to journalists, educating them about SCD so they can comfortably run programs on the topic. These efforts form a complete package, addressing the issue from all angles. Through this comprehensive approach, we can begin to control the prevalence of SCD.

Another crucial component of our program is research, particularly implementation research. We focus on two types: identifying what has worked and helped, and determining how to scale it up. For instance, we are conducting implementation science research in newborn screening. We have examined conventional diagnostic methods, which are expensive. The basic test found everywhere, hemoglobin electrophoresis, cannot detect SCD in infants under six months old.

We need tests that can detect the disease early. The expensive equipment we mentioned earlier is not sustainable here; the government purchased six units but has been unable to maintain them due to the high costs. Through research, we have found more cost-effective diagnostic methods using point-of-care technology, and we have demonstrated their effectiveness. We are now exploring how to scale up these methods to enable more widespread early testing.

These are some of the areas of research we are pursuing. We also need to investigate the genetic factors associated with disease manifestation in individuals, as we observe that even within the same family, the disease can present differently. Sometimes we can identify genes that modify the expression of hemoglobin or the disease itself. These genetic studies can lead to the discovery of new treatments for SCD.

The foundation for all of these efforts is education. Our educational program targets various groups, including policymakers. Sometimes, those of us at the forefront have information that is not widely available, and policymakers need access to this information to make informed decisions.

We also target the general public to increase awareness about SCD and reduce stigmatization of those affected. It is important to understand that SCD is a genetic condition, not an infectious disease, and it is not the fault of the individual. Patients with SCD need our help, understanding, and compassion. We need to ensure that they have conducive conditions in schools, are not bullied, and have the right infrastructure and support systems to thrive.

We need to educate healthcare professionals to support sickle cell patients using standardized approaches. We have developed multi-level standard of care guidelines for our healthcare system, covering tertiary hospitals, district hospitals, primary healthcare centers, and home care. These guidelines serve as training tools at different levels of healthcare and for parents, helping them understand how to care for affected children.

If truly implemented, these measures can help reduce the burden and prevalence of SCD in our country.

Regarding your question about government support, I have been involved in multidisciplinary research with colleagues within Nigeria and across Africa, supported by direct and indirect crowd funding.

The last question, being a health practitioner that has interacted with foreign counterparts, can you draw comparisons between Nigeria and other countries concerning the fight against SCD?

We are all collaborating because we have established several consortia. The most significant of these is the Sickle Pan African Consortium, (SPARCO) which has two coordinating centers, one located in South Africa and the other in Tanzania. SPARCO has sites in six African countries: Nigeria, Ghana, Mali, Tanzania, Uganda, Zimbabwe, and Zambia. Together, we are developing guidelines and conducting implementation research. We are also engaging in joint advocacy efforts. Additionally, we have initiated new collaborations with partners in the United Kingdom, Zambia and Ghana for patient centred management of sickle cell disease. Another project is the Sickle Cell Genomics Network of Africa led by Professor Solomon Ofori- Acquah from Ghana. We have completed data collection for that project and are currently analyzing the genomic data. Thus, we are involved in numerous collaborative efforts. Our work extends beyond mere collaboration. In Nigeria, for instance, we have established a network that the Sickle Pan African Research Consortium Nigeria Network with centres in the six geopolitical zone.

Do you have any message for the government

I am the Special Adviser to the Coordinating Minister of Health and Social Welfare on SCD. Therefore, it would be inappropriate for me to provide advice intended for the Minister through this medium. I deliver my recommendations directly to the Minister.

Thank you.

You are welcome!

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