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Rethinking Counseling Strategies for Curbing the Prevalence of Sickle Cell in Nigeria

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Abstract

Nigeria is the most populous country in Africa and has the highest number of sickle cell disorder with about 150,000 births annually WHO (2005). The term sickle cell disease SCD or sickle cell anemia SCA is a genetic condition which resulted by inheritance of homozygous sickle cell genes (SS) from both parents. The prevalence of the disease is enhanced due to lack of awareness and lack of blood screening before marriage. Though sickle cell disease has no known cure but is preventable so the need for proper awareness, campaign and counseling strategies such as premarital counseling, group counseling, speakers' bureau emphasized.

Introduction

Sickle cell anemia is a hereditary hematological disorder in human beings; it is a serious disorder and a global health problem with psycho-social implications, it is also associated by chronic anemia, unexpected episodes of illness and frequent

medical appointments which may impact the individuals' daily activities Alawale in Adebowale (2014). Nigeria has the largest sickle cell disorder with about 150,000 births annually as revealed by sickle cell foundation. Those with the disease suffer higher than average illness, world health organization (WHO 2005) estimated that more than 300,000 are born with severe forms of hemoglobin pathies worldwide each year; while 75% of all patients with sickle cell disease live in sub-Saharan African. Nigeria alone accounts for more than 100,000 new births every year.

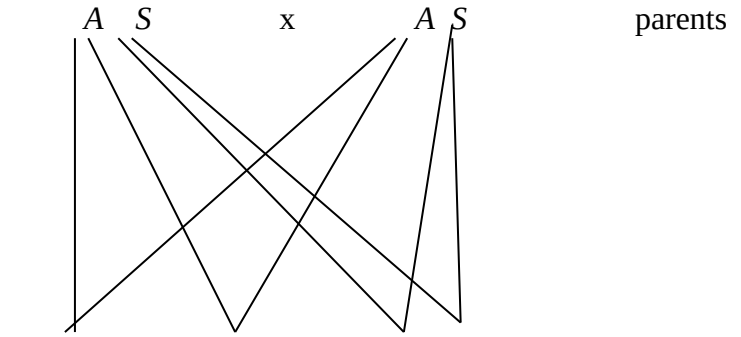
Sickle cell was first noticed and described as a peculiar elongated and sickle shape red blood cells in 1904 by intern Ernest Edward Iron when examining the blood of Walter Clement Noel, a 20 year old first year student from a wealthy black family in Grenada; Iron in collaboration with his supervisor Herrick wrote a paper published in 1910 in the Archives of internal medicine documenting the first known sickle cell disease in united states; Herrick was thus the first to characterize sickle cell disease, when he wrote a report about a patient who suffered from the strange disease with symptoms as asthmatic conditions and blood flow problems including body ulcer (Linde, 1972). The study led to the locating of new sickle cell hemoglobin (Hbs) that was predicted by Linus in (Johnson, 1984). Although the African medical literature reported the condition in 1870's when it was known in some areas as "obanjes" (children who come and go) because of the very high infant mortality rate caused by the condition.

Causes and Effects of Sickle Cell

Sickle cell disease (SCD) also known as sickle cell anemia (SCA) is a hereditary blood disorder, characterized by abnormality in the oxygen-carrying hemoglobin molecule in the red blood cells (NHLBI, 2010). This thereby makes the cells to assume an abnormal, rigid, sickle-like shape. SCD is associated with a number of acute and chronic health problems such as infections, severe body pains called sickle cell crises, the crises affect the bones, joints and other organs. These crises occur when sickle red blood cells block blood flow from the limbs and organs. The pain can be acute or chronic, but the acute is more common which ranges from mild to severe. The pain usually lasts from hours to as long as weeks. Repeated crises can damage the bones, kidney, eye, heart and liver and can also cause stroke. Some other effects of sickle cell disease are Delayed puberty in teenagers, Progressive anemia, Leg sores, Vision problems, it is mentally draining and also limits daily activities, and has a high risk of death.

Sickle cell disease occurs when a person inherits two abnormal copies of the hemoglobin gene, from both parents. When the hemoglobin **S** gene is inherited from only one parent and normal hemoglobin **A** gene from the other, a person is said have sickle cell trait. People with the trait are generally healthy, only in rare cases do they have complications similar to those seen in people with sickle cell disease.

Example of an inherited pattern of sickle cell disease and sickle cell traits using Mendelian's crossing



Ratio 1:2:1

Form the above illustration, it shows how sickle hemoglobin genes are inherited. A person usually inherits two hemoglobin genes one from each parent. A normal gene will make normal hemoglobin (A) and a sickle gene will make abnormal hemoglobin (S). When both parents have a normal and abnormal gene, HBAS, each child will have a 25% chance of inheriting two normal genes, a 50% chance of inheriting one normal and one abnormal gene and a 25% chance of inheriting two abnormal genes. This is just to indicate the chance of prediction of the children genes, it does not indicate how the inheritance is going to be. Many people tend to be deceived by the above chance indicator to go into marriages with the assumption that only the fourth child will inherit two abnormal genes (SS), on the contrary, that is not the reality because with each conception, both chances may occur that is either AA, AS, or SS. So therefore, it is of great importance for intending couples to go for genotype testing before going into marriage.

The Prevalence of Sickle Cell Disease in Nigeria

Nigeria is the most populous country in Africa and has the largest number of patients suffering from sickle cell anemia (Center for Disease control & prevention, 2011).

The incidence of sickle cell trait and anemia in Nigeria is 20% and 5% respectively (WHO, 2005). There is an obvious lack of information and education about the disorder in Nigerian society. The prevalence is enhanced due to encouraged growth of myth, children with sickle cell are referred to as " obanjes" by Yoruba's and "abiku" by the Igbo's i.e children that come and go or evil child, this is due to the high death rate associated with sickle cell disorder at tender age Vanguard (2011). Another factor responsible for high rate of sickle cell disorder is Misinformation, whereby people are being giving wrong information about sickle cell disease due to lack of adequate medical facilities in rural Nigeria especially the rural parts of northern Nigeria, for instance, children with SCD are most at times in these areas seen as children with bad luck or who are been possessed by evil demons. Inappropriate information is also a factor that fosters the prevalence of sickle cell in Nigeria, individuals or intended couples are at times misinformed about how the inherited pattern is, that is to say couples that have AS as their genotype have 25% chance to have a sickle cell child for each conception, instead of the assumption most couple have, that only one out of every four children is likely to have sickle cell disease. Frustration; people with SCD, like those with other chronic health conditions, may be at risk for psychosocial or mental health problems including depression, self concept and peer socialization difficulties. Swanson, Grosse and kulkarni (2011). lack of premarital counseling before going into marriage, where by intending couples get married without knowing their genotypes, they get married even when their blood genotypes isn't compatible therefore increase the rate at which sickle cell patients are giving birth to.

Irin (2008) report that at least 100,000 die from sickle cell disorder in Nigeria every year making it the number one sickle cell endemic country in Africa. Based on world Health Organization, (WHO, 2005) Nigeria accounts for 75% of infant sickle cell case in Africa and almost 80% of infant death form the disease in the continent.

According to WHO, sickle cell is particularly prevalence in areas of high malaria transmission. Around four million Nigerians are estimated to suffer from the disease, while 25 millions others carry the genes which they pass to their offspring.

Problems associated with living with sickle cell disease

Sickle cell patients or being neglected and are often seen as junkies using their health as an excuse to get a fix, some of the challenges being faced are:

At Home

Sickle cell patient faced challenges at home some of which are:

1. They are expected to act like other siblings in the family, in terms of routines
2. Most of the individuals living with SCD are trying to leave just like their counterparts, there by restricting by parents are seen as inferiority by them.
3. Parents should give them freedom to live and association with others but caution them to avoid activities that can triggers the condition, such as football, exposure to cold and mosquitoes, strenuous exercise and so on.
4. There is misconception that when students with sickle cell disorder reach certain age, they will stop having pain crises. Most families are with this view therefore tends to neglect the children with the sickle cell disease when they needed them most.

At School

Students with sickle cell disease also face a lot of challenges at school, some of which are:

1. They are considered as normal students in term of schools routine whereby where there are forced to do activities such as sweeping, sport activities and are being given hard punishment.
2. Student with sickle cell disorder usually experience traumatic condition which often lead to them been absent in school/class for days or even weeks. Despite that no consideration are provided for them such as make up lessons, lectures, test or exams.
3. Students with sickle cell anemia are usually advice to drink a lot of water so as to avoid dehydration, in most of our classes or schools, there is no provision for them. Also drinking a lot of water which makes them urinate frequently demand going out, which as well become difficult for teachers to condone; they are punished by seniors or even teachers without consideration for their plight.
4. Those with SCD even when not sick are always struggling to endure pains in one part of the body or the other there by making concentration and undergoing the school activities difficult for them .While the school assessment tend to rate their performances in comparison to normal learners with no special regard to their situation in evaluating educational outcomes. Mean while they are expected to behave and act as the normal students.

5. Negligence and misconception is one of the major problem faced by student with sickle cell, they are seen as pretenders or complainers by their mates, and are neglected by the teachers. The teachers should at least have consideration for student with SCD, if possible there should be different way by which they are evaluated due to their situations. They are neglected and teased by their mates, when they are sick; no one is helping them in coping with the trauma being faced.

Counseling Implications

Sickle cell disease is a life long illness and has no available cure until now. Though cost effective treatment exists for pains and other aspect of the disease. Therefore preventive measures are still more effective in dealing with disease and reducing its prevalence in Nigeria, Counseling is hereby another alternative to dealing with SCD. Counseling is the activity of the counselor, a professional who counsel people i.e give them guidance and assist them especially on personal problems and difficulties. Some of the areas of counseling include career counseling, clinical counseling, conflict resolution, and social psychology to mention but a few. Some of the Ways by which counseling help with the management and prevention of SCD are:

Genetic counseling

This is a process by which the patients or relatives at the risk of an inherited disorder are informed of the nature and consequences of the disorder and the probability of transmitting it. Through this process, SCD can be prevented as individuals will be aware of the problem. Genetic counselors in collaboration with the health care team create advocacy for the disease, they also form informed choices and ways to adapt to the condition, education about testing, management, and prevention of the disease, also help in accessing the chance of the disease reoccurring by the interpretations of medical and family history (UNESCO, 1995). By this process of genetic counseling, individuals hereby get access to the counselor for the counseling process, this will invariably help in the eradication of SCD to the barest minimum and will help those with the condition to adapt and manage themselves efficiently.

Public Education

Accurate, current and clearly written information about sickle cell should be produced, translate into various languages and made widely available to people. Different forms of communication can be used such as the mass media, fliers,

magazines, newspapers, the internet, seminars and workshops both in hospitals, schools and organization, this will make people aware of the condition and how to prevent the future generation form such deadly disease.

Speakers' bureau

Establishment of active sickle cell patients organization or club, where by the patient come together and organize a specific month for their meeting and creating awareness. These organizations should have branches in every state of the federation and should include patients, parents, medical personnel's, qualified counselors and governmental and non-governmental firms. Sanitizations inform of rallies, jingles in TV and radios stations, posters on bill boards should be used as the tools in fighting against SCD. A counselor can help in organizing and managing the ways these will be achieved.

Group Counseling

The major clinical problems associated with SCD are influenced by the age of the individuals. Counseling sessions should be organized in groups of varying ages such as children, adolescents and adults. Topics on how to manage and control the associating clinical conditions should be dealt with, thereby enhancing the transmission of information to a large number of individuals at the same time.

Counseling Therapy

Sickle cell disease can be stressful, at times patients may feel depressed, rejected and stigmatized; professional counselors should be available at every sickle cell clinic nationwide to work in collaboration with the medical teams in providing counseling therapy, to resolved and handle problems faced by the patients towards having a self fulfilling happy life, and to enable them live positively with the disease despite its complications and devastating consequences.

Premarital Counseling

Premarital counseling is a type of counseling given to youth's or prospective couple to guide against passing the sickle genes to offspring, and to give hope to carriers and sufferers and positive save ways of having suitable marital partners. People with **AA** genes need to be encouraged to marry those with sickle cell trait (AS) and sickle cell disorder (SS).

Premarital counseling is better given early enough before the two love birds get so engaged or becoming inseparable as being usually perceived by those involved. The counselor will discuss so many issues in which blood compatibility in term of genotype is explained. Parental involvement to ensure proper matching of suitors become paramount, the truth therefore have to be said whether sweet or bitter, if the intended couples both have AS as their genotype they should be made to understand the repercussion, the high probability of their children having SCD and other associated problems, with the pains and stress they are likely to encounter in the area of rearing children. Though many of the youth are love intoxicated before going for the genotype, the advice may not be meaningful to them, but other people experiences that have suffered such menace can be shared with them.

In marriage counseling should also be made available to couples, especially those having children with sickle cell disorder on ways to manage the disease and prevent complications.

Healthy Interpersonal Relationships

Interpersonal relationships dynamic system that involve a good and smooth relationship between the care givers, counselors and patients, in order to give them hope, encouragement and enhance survival of sickle cell can collaborate between the Federal Ministry of Health, state and local governments stake holders and care givers in providing adequate facilities and funds to help those living with sickle cell disease and also enhance flow of information's about SCD thereby creating awareness to the general public.

Transition Programme

To eradicate sickle cell problem from the society, the system of catching them young can be adopted (Adebowale, 2014). Human life is transitory from childhood to adulthood thus awareness programmes should be deeply rooted; from childhood in primary school, to secondary school into tertiary institution as part of educational curriculum, or school club and association to spread awareness and also give hope to students living with the disease.

Conclusion

Sickle cell disorder presents a special challenge to African and Nigerians in particular, as it affect virtually every extended family. Every individual has the right

to live, so this problem demands that we squarely accept it as a major challenge and demonstrate our ability to effectively plan for the future of our children and give them the chance to live a happy and well fulfilling life.

Recommendations

Based on the discussions above, the writer recommend following which if to practice will help in curbing the prevalence of sickle cell disorder.

1. There should be a strong national sickle cell disease control programme, the programme should includes advocacy, prevention, early detection, treatment and counseling.
2. School programme system teaching should give special consideration to learners living with the disease and their teaching and learning interaction.
3. Partnership should be enhanced between parents, patient's health professionals, relevant community interest groups, media and the general public, this will thereby enhance and facilitate awareness and active participation in care and prevention programmes.
4. Premarital screening and counseling should be enforced for couples approaching marriage, this would allow individuals to make informed decision on mate selection and will wish to avoid the risk of child with sickle cell disease.
5. Couples who are married without knowing their genotypes, should also be counseled to go for genotype testing, and if there is possibilities of having children with sickle cell disorder, they should be informed of ways to cope and prevent complications of the disease and challenges associated with the disorder.

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