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**SICKLE CELL ANEMIA AND ITS IMPACT ON FAMILIES.**

It is of great relief that the world is evolving to know more about sickle cell anemia. The act of ignorance has cost a lot of people their lives. Many are still going through this path of ignorance and it is high time the society is more informed and enlightened.

Sickle cell anemia which is a specific type of sickle cell disease(SCD), is a genetic disease of the red blood cells(RBCs). Normally, red blood cells are shaped like discs, which gives them the flexibility to travel even through the most minute blood vessels. However, with this disease, the red blood cells will mutate to have an abnormal crescent shape resembling a sickle. This makes them sticky and rigid making it prone to getting trapped in small vessels, thus blocking blood flow and oxygen from reaching different parts of the body.

The cause of sickle cell anemia is defective gene, called a sickle cell gene. People with the disease are born with two sickle cell genes, one from each parent. If someone is born with one the sickle cell gene, it’s called sickle cell trait. People with sickle cell trait are generally healthy, but they can pass the defective gene on to their children. Thus, making them the carrier of the gene. Sickle cell anemia is more common among Africa, Caribbean, middle eastern, eastern Mediterranean and Asian descents.

Symptoms of the victims of sickle cell anemia can be severe and threatening. The symptoms usually show up at a young age. They may appear in babies as early as four months old. These symptoms include: periods of pains that last a few hours to a few days, blood clots, swellings in the hands and feet, joint pain that resembles arthritis, chronic neuropathic pain (nerve pain), life threatening infections, anemia (decrease in red blood cells), jaundice and so on.

Sickle cell anemia can however cause severe complications, which appear when the sickle cells block vessels in different areas of the body. Painful or damaging blockages are called sickle cell crisis. They can be caused by a variety of circumstances, including: illness, changes in temperature, stress, poor hydration, altitude. The complications that can result from sickle cell anemia are; splenic sequestration which is a blockage of the splenic vessels. It causes a sudden painful enlargement of the spleen. The spleen may have to be removed due to complications in an operation known as splenectomy. Patients without spleen are at higher risk for infections from bacteria. Delayed growth is also another complication. Children are generally shorter but regain their height by adulthood. Sexual maturation may also be delayed, this happens because as stated earlier, sickle cell red blood cells cannot supply enough oxygen and nutrients. There are simple steps that people with sickle cell can take to help prevent and reduce the number of pain crises. They include the following: drinking plenty of water, avoiding places or situation that cause exposure to high altitudes (e.g. Flying, mountain climbing). Adults with severe sickle cell anemia can take a medicine called hydroxyurea and are checked often by a doctor to prevent complications, including an increased risk of infections.

As the world keeps evolving, scientists have been researching and examining ways to formulate a cure for sickle cell anemia. Stem cell or bone marrow transplant is being used for patients with severe sickle cell anemia who have a matching donor. Children younger than sixteen years of age who have severe complications and have matching donor are the best candidates. Though, there are other ways sickle cell anemia can be treated., which include: blood transfusion that helps in transportation of oxygen and nutrients needed. Supplemental oxygen is also given to treat sickle cell anemia which makes breathing easier and improves oxygen levels in the blood.

**The impact sickle cell anemia has on families.**

1. To care for a family member with sickle cell anemia most especially that of a child, adversely affects the basic needs of the family such as food, shelter, clothing. This is not surprising considering the rising trend of inflation in this period of global economic recession and socio-political instability. Most of the time spent caring for them makes the family lose income or financial benefits even going to the extent of job loss. Many families set out loans to meet the expenditure of the patient’s illness especially in countries like Nigeria where national programs on health insurance and social welfare systems are absent, making caring for a child with chronic illness such as sickle cell anemia a great financial burden.
2. Caring for a child with sickle cell anemia can make caregivers neglect other family members sometimes or frequently. This act is not intentional obviously but it just comes naturally because of the demand caused by the child’s illness. It is known that the way parents relate with their ill children and the feeling of neglect this generates in other siblings is a major factor in family dysfunction. This neglect, especially when experienced too frequently has been described as a risk factor in the psychopathology of psychosocial problems in chronic physical illness. It has also disturbed recreational activities in homes. The illness can make it difficult for other members of the family to engage in gainful activities such as going to the market or parks.
3. Sickle cell anemia has also affected the family life and interaction. It has caused hostility or a bit of tension in the family. Quarrels are frequently sprouted up between couples because of the child illness, which can later extend to marital disharmony. It has also disrupted family interactions. The reason for this may be because of the perfecting effect of the extended family structure, culture, religion, especially in countries like Nigeria where beliefs are influenced by cultural and religious values, which in turn influence health behavior and coping strategies.
4. Researchers have also come in agreement that depression is one of the impact sickle cell anemia has on the family. Many caregivers result in feelings of depression, sorrow and anger towards themselves and the affected child. The unevenness in the coping ability of the caregivers may not necessarily be a consequence of the callousness of the clinical condition of the child, but several other factors such as the socio-demographic characteristics of the caregivers or the social or family support available to them. Many caregivers of sickle cell anemia patients experience considerable psychosocial impairment from their children illness.
5. Parents or care givers of sickle cell patients tend to have worse health related quality of life, compared to those without sickle cell children which impacts negatively on their behavior and self-esteem.

Sickle cell anemia is not the end of the world and people with it can still achieve great height. I personally feel that the government should strengthen the existing national health insurance as well as subsidizing the cost of sickle cell anemia care to alleviate the huge financial burden on family. In addition, regular psychological support should be provided to caregivers or families members to alleviate their burden.

Finally, genetic counseling can go a long way in helping families prevent sickle cell anemia given the fact that it is an inherited disease of which both parents must be carriers of the sickle cell gene for a child to be affected.