Sickle Cell Anemia and its Effects on Education

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Background Information

Sickle Cell Disease was discovered in 1910 by a man named James B. Herrick (Winter). According to William P. Winter, Sickle Cell Disease had been present in Africa for at least five thousand years, but people knew nothing about it until its discovery in the United States in 1910 (Winter). The first known person with Sickle Cell Disease was Walter Clement Noel, who was a dental student from Grenada (Winter). He had gone to Dr. James Herrick with complaints of pain and symptoms of anemia (Winter). Noel was sent to Dr. Ernest Irons, who conducted several tests on Noel and realized that his red blood cells had a "sickle shape (Winter)." In 1927, Hahn and Gillespie determined that when oxygen is removed from the blood cells that they began to sickle (Winter). By the late 1940's and early 1950's people started to realize that Sickle Cell Disease is hereditary. Col. E.A. Beet and Dr. James V. Neal were accredited with the discovery of Sickle Cell Disease as being hereditary, and people with the trait were heterozygous and the people with the diseases were homozygous (Winter). It was not until 1951 that other forms of sickle cell were discovered, but Sickle Cell Disease was found first in people of African descent.

Sickle Cell Disease originated in West Africa and had five separate mutations (Maakaron & Taher, Sickle Cell Anemia, 2014). Four of these mutations are in Africa and one that is more prevalent in India and the Middle East (Maakaron & Taher, Sickle Cell Anemia, 2014). Sickle cell anemia is an inherited blood disorder that affects red blood cells. The sickle cell gene causes the body to produce abnormal haemoglobin, which clump together causing the red blood cells to become stiff and develop a C- shaped or sickle form. Once these cells sickle, they can block blood vessels and reduce the flow of blood to certain parts of the body. According to the CDC there are six different types of Sickle Cell Disease, which are HbSS, HbSC, HbS beta thalassemia, HbSD, HbSE, and HbSO (Centers for Disease Control and Prevention, 2014). HbSS
Sickle Cell Anemia is the most severe form of Sickle Cell Disease, and people who have this form have inherited two sickle cell genes, one from each parent (Centers for Disease Control and Prevention, 2014). Sickle cell anemia is known as a haemoglobin disorder. Haemoglobin disorders are inherited blood diseases that affect how oxygen is carried in the body (Centers for Disease Control and Prevention, 2014). As I stated early sickle cell disease is characterized by the sickle shape of the red blood cell, and because of the lack of plasticity, which impairs the flow of blood, which causes the shortened red blood cell survival (Centers for Disease Control and Prevention, 2014). Due to reduced blood oxygen levels and blood vessel blockages in people with sickle cell anemia, they often experience chronic acute pain syndromes, severe bacterial infections, and necrosis, which is known as tissue death (Centers for Disease Control and Prevention, 2014). General symptoms of sickle cell anemia in infants are fever, swelling of the hands and feet, pain in the chest, abdomen, limbs, and joints, nosebleeds and frequent upper respiratory infections (National Institutes of Health, 2012). The symptoms in children are fatigue and shortness of breath, irritability, and jaundice and as they develop in adolescence and adulthood they begin to experience delayed puberty, severe joint pain, progressive anemia, leg sores, gum disease and vision issues (National Institutes of Health, 2012).

According to the CDC, sickle cell crises are episodes of pain that occur with varying frequency and severity and followed by periods of remission. The pain has been described as being equivalent to cancer pain and more severe than postsurgical pain. It occurs in the lower back, leg, abdomen, and chest and generally recurs in the same areas. During the crisis, it is important to assess the pain to determine if that person needs to go to the doctor or if that person could be treated at home (National Institutes of Health, 2012). The lifespan of an individual with sickle cell anemia in 1973 was 14 years old, and now they reach the age of 50 or older.
Statistics shows that approximately 5% of the world’s populations are healthy carriers of the gene for the sickle cell trait and in some regions have as high as 25% in some areas. According to the CDC, more than 70,000 people in the United States alone have sickle cell disease (Centers for Disease Control and Prevention, 2011). There are also two million people in the United States who have the sickle cell trait (Centers for Disease Control and Prevention, 2011). This statistic does not account for people who do not know that they have the trait. The people that are most affected by sickle cell anemia are African-Americans and Hispanic-Americans.

According to the CDC people that are at risk of inheriting the gene for sickle cell descend from people who are or were originally from Africa, parts of India and the Mediterranean (Centers for Disease Control and Prevention, 2011). They also stated that about 40% of people in certain areas of Africa and about 9% of African-Americans have the sickle cell trait (Centers for Disease Control and Prevention, 2011). Studies also show that 1 in 500 African-Americans and 1 in 1,000-1,400 Hispanic Americans is born with sickle cell disease (Centers for Disease Control and Prevention, 2011). The CDC also reports that the sickle cell trait occurs among 1 in 12 African Americans (Centers for Disease Control and Prevention, 2011). These statistics show that although both African-American and Hispanic-Americans are able to contract the disease, the African-American community is heavily impacted by sickle cell anemia.

There are a few treatment options for people with sickle cell anemia. These options include blood transfusions, hydroxyurea, penicillin, folic acid, iron chelators, antiemetics, and many others (Maakaron & Taher, Sickle Cell Anemia Medication, 2014). There are a few ways that it could be prevented by having both parents screened for the trait to see the probability of the child having sickle cell anemia. It is also important to have your kids get tested for it at a young age for Sickle Cell Disease so that the child can begin treatment before they start to have
complications. These tests are important because children with Sickle Cell Disease tend to form other infections as diseases such as meningitis, hand-foot syndrome, acute bone pain crisis, osteonecrosis, and osteomyelitis (Maakaron & Taher, Sickle Cell Anemia Clinical Presentation, 2014). Hand-Foot Syndrome is one of the more common ways that people find out that their child has Sickle Cell Anemia. Hand-Foot Syndrome is usually characterized by the swelling of the hands and feet of young children. According to the World Health Organization, it can also be prevented by having a neonatal diagnosis, which will allow the provision of simple protective measures (World Health Organization, 2006).

Sickle Cell Disease is a relatively new disease to the United States but has been affecting people of African descent for thousands of years. Sickle Cell Disease affects adults, but the children end up being the ones who suffer the most from the episodes of pain and trying to understand the things that they have experienced. I truly believe that children have it the worst because they have to be constantly in the hospital experience the same amount of pain that is hard for an adult to bear. Understanding Sickle Cell Disease and the way that it affects children’s educational attainment is important in helping to implement programs to help with their educational development.

Knowledge Regarding Sickle Cell Disease

One of the most interesting findings for me is the realization that most people fail to understand what Sickle Cell Disease is and the way that it affects them while in their reproductive years. When I have discussions about SCD with family and friends, there is a clear understanding that a good majority of them have heard of the disease, but fail to fully understand the extent of the disease and the way that it affects the body. The fact that African Americans are more likely to be born with SCD, but fail to fully understand it and the way that it manifestation
is astonishing to me. In the article “Inadequate Community Knowledge about Sickle Cell Disease among African-American Women,” there were 162 African American women that were surveyed by telephone, and this survey was conducted to measure the women’s understanding of Sickle Cell Disease. The end result of this study was that African American women are poorly informed about the genetics associated with having a child with SCD (Boyd, Watkins, Price, Fleming, & DeBaun, 2005). This is problematic because for people of African Descent it is important to know whether you have the Sickle Cell Trait or not. As previously stated there is a 25% percent chance that if both parents carry the Sickle Cell Trait that their child might end up having Sickle Cell Disease. As long as both parents know their statuses, then there is a greater chance that those parents will be better equipped to take care of a child with SCD.

Sickle Cell Disease and Education

According to the article “Risk and Resilience Factors for Grade Retention in Youth with Sickle Cell Disease,” children with SCD are at risk of poor academic performance due to the neurocognitive effects of their disease (Ladd, Valrie, & Walcott, 2014). The fact that SCD can cause children to have strokes, which could be silent or overt, can result in issues with attention, memory, and executive functioning (Ladd, Valrie, & Walcott, 2014). This is an issue because children are expected to retain certain amount of information as they matriculate through school. Having a child that may have silent strokes that cause them to lose some of their memory as well as making it harder for them to pay attention causes them to have to work twice as hard in order to succeed. Studies show that cognitive deficits due to silent infarcts or major cerebrovascular accidents occur in almost 30% of children before age 6 (Knight-Madden, Lewis, Tyson, Reid, & MooSang, 2011). This shows the importance of cognitive rehabilitation to children who have experienced issues with memory, attention, and executive functioning because some people do
not even know that their child has had a stroke until their child goes to the doctor to receive a CAT scan. It is also important to catch it early because with most kids that have issues with cognitive development, it puts them further behind their healthier counterparts before they even get to primary school.

Absenteeism and Sickle Cell Disease

According to the documentary Sickle Cell Patient Stories- Children’s Hospital Los Angeles, pain from Sickle Cell Crisis in children can last between five to seven days (Children's Hospital, 2009). With children having to spend such an extended amount of time in the hospital, there should be certain things in place to ensure that they will not fall behind their healthier counterparts. In the article “The Possible Impact of Teachers and School Nurses on the Lives of Children with SCD,” it discussed the importance of having work sent to the hospital with the child in order to make sure that the student is able to complete assignments on time (Knight-Madden, Lewis, Tyson, Reid, & MooSang, 2011). This is a great idea because it prevents grade retention and gives that child something to do while being hospitalized. It also helps to reinforce the idea of the teacher as having a certain responsibility to the child even though they have to accommodate that child and make sure that they are assisting that child when needed. The article “The Real Effects if Sickle Cell Disease on Children and Adolescents,” brought up a great idea that multimedia communication could be used to connect hospitalized children with teachers and schools, with other people with the same illness, and it would allow children to be involved in special events (Grove, Grove, & Michie, 2013). Implementing a program that allows children with Sickle Cell Anemia to be able to do things with children who understand what it is that they are going through allows for the children to still be able to be social. This also takes care of the
issue of absenteeism because it allows them to be able to be in a classroom setting while being hospitalized until the pain is over.

Conclusion

After looking at the literature that is already out there on SCD and its effects on children’s educational attainment, I have come to realize that every child’s situation is different. There are some children who were born with SCD, but were able to get the bone marrow transplant which cured them of the disease. This is not typical of every child and educators and well as the parents have to work together to make sure that children are getting everything that they need to succeed in school. There needs to be further research looking at the effects of absenteeism and educational success. There also needs to be more research that is conducted on the basis of ways to educate everyone in the black community about SCD as well as the Sickle Cell Trait. With us being in the age of technology there needs to be research looking at ways to lower recidivism rates among children with SCD allowing them to still be a part of the classroom, but just from the hospital.
Bibliography


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