Parent Involvement in Education of a Child with Sickle Cell Anemia.

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ABSTRACT

The disorder we call "Sickle Cell Disease" had been present in Africa for at least five thousand years and has been known by many names in tribal languages. People with SCD have abnormal hemoglobin, called hemoglobin S in their red blood cells. The objective of the study was to establish how parents are involved in management of their children with sickle cell anemia to access formal education. The methodology of study snowball is a non-probability sampling technique where existing study subjects recruit future subjects from among their acquaintances. The study found out that most of the parents discovered about the condition through hospital testing but some few tried the herbs. The study found that majority of the family members had positive relationship with the sickler and most of them empathize with the child in this condition. However some members of the extended family including some parents had mixed reactions. The study found that parents give their children a variety of porridge which balanced. It was found that maintaining the child in this condition together with education was expensive. It was established that the children mostly attend regular schools. The parents are aware of the rights of the child rights to access education however this may be interfered with by crisis. The government should avail medical facilities. Teachers train in special education should be posted to these schools. Parents should be made aware of condition of this disease.

Key words: 1. Sickle cell 2. Hemoglobin 3. Nyamuoda 4. Ododo 5. Omena.

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The disorder we call "Sickle Cell Disease" often abbreviated as SCD, had been present in Africa for at least five thousand years and has been known by many names in tribal languages. In Luo comunity in Kenya it is referred to as "Tuo Remo" because of frequent lose of blood in the body, and transfusion is to be done. According to Winter (2010) What we call its "discovery" in 1910 occurred in the United States. This was when a young man from the island of Grenada, a dental student studying in Chicago, went to a Doctor with complaints of pain episodes, and symptoms of anemia. The term sickle cell disease (SCD) describes a group of inherited red blood cell disorders.

People with SCD have abnormal hemoglobin, called hemoglobin S or sickle hemoglobin, in their red blood cells. Hemoglobin is a protein in red blood cells that carries oxygen throughout the body. "Inherited" means that the disease is passed by genes from parents to their children. SCD is not contagious. A person cannot pass it on like other viral infections such as Corona and HIV and AIDS. People who have SCD inherit two abnormal hemoglobin genes, one from each parent. In all forms of SCD, at least one of the two abnormal genes causes a person's body to make hemoglobin S. When a person has two hemoglobin S genes, Hemoglobin SS, the disease is called sickle cell anemia. This is the most common, fatal and often most severe kind of SCD (Mayo Staff, 2020)

Sickle cell anemia is an inherited form of anemia — a condition in which there aren't enough healthy red blood cells to carry adequate oxygen throughout ones body. Normally, the red blood cells are flexible and round, moving easily through ones blood vessels. In sickle cell anemia, the red blood cells become rigid and sticky and are shaped like sickles or crescent moons. These irregularly shaped cells can get stuck in small blood vessels, which can slow or block blood flow and oxygen to parts of the body. It is a permanent condition and no cure for

most people with sickle cell anemia. But treatments can relieve pain and help prevent problems associated with the disease (Mayo Clinic Staff, 2020, Sojeant. 2013).

It has been reported that most of the world's Sickle Cell Disease (SCD) burden is in Africa, where it is the major contributor to the child's morbidity and mortality. Despite of the low cost of many preventive SCD interventions, insufficient resources have been allocated and progress of alleviating the sickle cell burden has lagged behind other public health efforts in Africa (Oron et al,. 2020). There is evidence that the greatest burden of SCD is in sub-Saharan Africa, where access to medical care and public health strategies to decrease mortality and morbidity are not uniformly available. Over 300,000 babies are born with SCD annually; this number is expected to increase to up to 400,000 individuals by 2050. This can be remediated through early diagnosis of SCD to improve survival. However, only a few centers in sub-Saharan Africa are able to initiate newborn screening and deliver comprehensive health care at an early age. Most other individuals are diagnosed when they present with a complication of disease (Debaun and Galadanci, 2020). This condition is not new in Africa.

In Kenya, Kilifi area a study revealed that although morbidity and mortality were high in young children with sickle cell disease in this Kenyan cohort, both were reduced by early diagnosis and supportive care. The emphasis must now move towards early detection and prevention of long-term complications of sickle cell disease (Uyoga et al, 2019). It is therefore imperative to establish how those who survive to school age are accessing education with parental involvement. Although the prevalence of sickle cell trait (SCT) was known, the magnitude of SCA was yet to be established. SCD has its highest prevalence in malaria endemic regions mainly the Coast and Nyanza regions in Kenya, (Kuta, Njuguna, Tenge and Ganda, 2020). There is need to ascertain the access to academic services in Kenya as a right of every child with other health impairments among Persons with Disabilities in Kenya. Based on this background, the study wished to establish the parental involvement on access to education of their children with SCD in Siaya County, Kenya, therefore the study had one objective.

The objective of the study was to establish how parents are involved in management of their children with sickle cell anemia (SCD) to access formal education.

METHODOLOGY

In sociology and statistics research, snowball sampling (or chain sampling) is a non-probability sampling technique where existing study subjects recruit future subjects from among their acquaintances. Thus the sample group is said to grow like a rolling snowball. Snowball sampling consists of two steps: The first step in this study only one participant was known and identified in the population that was initially found. In the second step, the initial participant provided another person and the population grew. The study used linear snowball sampling. This is where the formation of a sample group starts with one individual subject providing information about just one other subject and then the chain continues with only one referral from one subject (Question Pro, 2021). This pattern is continued until enough number of subjects is available for the sample. It was difficult to locate the respondents; at the same time there was no already prepared list to use for sampling. It was easier and cost effective to find the sample. Through this method the researcher sampled 15 respondents which were considered enough for qualitative research to analyze the data collected. Qualitative method is used to understand people's beliefs, experiences, attitudes, behavior, and interactions. Creswell (2013) observe that qualitative researchers use an emerging qualitative approach to inquiry, the collection of data in a natural setting sensitive to the people and places under study, and data analysis that is both inductive and deductive and establishes patterns or themes. This study was purely qualitative.

Objective: To establish how parents manage the conditions of their children with sickle cell anemia to access formal education.

Questionnaire for Parents.

1). How did you discover that your child has Sickle cell Disease?

2. How do other family members relate to the child in his/her health condition?

-what kind of food do you give the child? (Probe)

-what kind of uji mixture do give the child?

3. Have you tried other sources in trying to treat the child? (Probe)

4. Describe your experiences of taking care of child?

5. Does the child attend formal education?

6. Where does the child attend school ie day, boarding, special school or integrated?

7. Who pays fee the child's fees and any other school levy?

8. What awareness do you have on the right of the child to access education?

9. How do you deal with cold weather changes in school? (Probe)

10. How do you generally manage the child to continue with learning in school?

11. What experience do you have on the education of the child?

12. How do you relate with the school administration in terms of education of the child during school days?

13. What do you think school teachers should to assist the child in the learning process to improve his/her academic performance?

14. How do you maintain the child during crisis/episodes to ensure the child does not loose much in academic performance? .

15. What expenditures do you incur in order to maintain the child at school?

16. What challenges do you face in the education of the child?

17. What future plans do you have for your child after school?

DISCUSSION OF FINDINGS

One of the items required, was to find out how parents discover that their child has a sickle cell. The study found out that most of the parents discovered about the condition through hospital testing but some few tried the herbs (African traditional medicine) as revealed by the following observations: This was reported by parents as follows:

I discovered when I took the child to hospital. The child was having frequent malaria,

Testing was done in the hospital. (P1)

The child was a sickler, the body was pale. He was having frequent pain in the joints.

He was also having chest pain. (P2)..

I tried herbs but were not effective for over one year. Later I took the child to the hospital

Where he was tested of malaria and sick cell symptoms. (P 15)

Another parent observed that often blood level was low especially during cold weather. Walking became difficult. The foot was paining; during crisis there was pain in most parts of the body. (P11)

I took the child to the hospital I thought it was malaria. I even tried herbs at the same time

from the community. There were several admissions in the hospital. There was multiple pain and was tested. The child was put on normal drip. He was found to be having malaria and low blood level. (P 3).

I discovered when the child was about one year and seven months. I took the child to Jaramogi Oginga Odinga Teaching and Referral Hospital in Kisumu in 2015. The child was having a lot of crises even after that. (P 10)

The findings concur with William (2020) who stated the following symptoms as the stomach was swelling, swelling of hands and feet. The swelling is caused by sickle-shaped red blood cells blocking blood flow to the hands and feet. The major features and symptoms of sickle cell anemia include: fatigue and anemia pain crises dactylitis (swelling and inflammation of the hands and/or feet) and arthritis ,bacterial infections, Sudden pooling of blood in the spleen and liver congestion, Lung and heart injury, leg ulcers, asepti,necrosi and bone infarcts (death of portions of bone) and eye damage. Some features of sickle cell anemia that can occur at any age include: fatigue, Anemia ,pain crises and bone infarcts. However the study found out that some of the parent tried the use of traditional medicine to try to diagnose sickle anemia. Ameh, Tarf and Ebeshi (2012) revealed that antisickling herbs are common in West Africa and that more are still being discovered however it appears that what is happening in other parts of Africa on traditional medicine are not realized uniformly in every region as was found by the current study that traditional medicine was no very effective in this region of Africa, Kenya which is part of East Africa. The findings also does not concur with Moji and Monika (2016) who revealed that patients' narratives focused on two main themes: lay understandings of how SCD works (using ideas of attack and fortification, and blockage and flow); and what causes the illness (lay ideas of inheritance).

The most common description of SCD was that their white blood cells were 'eating/sucking out/feeding on' their red blood cells. Hence, treatment required 'building up' their blood, while a key to good health was ensuring an unimpeded flow of blood. Most participants believed SCD was hereditary, but there were various understandings of the mechanism and probability of its transmission. Belief in the possibility of transmitting SCD was not always a barrier to reproduction, nor did participants always insist on their partner or child being tested.

The study also wanted to establish how other family members relate to the child in his/her health condition. The parents revealed the following:

Majority of the family members support the child. The first time it was discovered that condition runs in the family. The father had two wives, the fourth child in the first house had a sickle cell, he was a boy, the girl survived. The other house had no signs but the sickness was discovered among grand sons and granddaughters. On of the granddaughters had five sons and one girl who was a affected and a sickler. Therefore the family members were familiar with condition. (P1).

My child is first born; the rest of the family understands her although other members of extended family have got mixed reactions. (P 4).

Relationship is good, extended family are afraid questioning the source of the disease. (P 5).

The relationship is good except that sometimes the child is withdrawn and moody. (P 8)

This finding is not concurrent with Burley, Evans and Oler (2006) who concluded that their research suggests that the primary parent in such a family experiences additional emotional strain much like primary parents of children with other chronic illnesses have been found to exhibit. The research also suggests that the ill child's presence influences interpersonal relationships within the family. Specifically, there is some evidence that the relationship between the parents and other offspring may be affected adversely. The findings also concurs with Adegoke and Kuteyi (2012) who observed that the level of support given to SCD children may reflect the dynamics of intra-family relationships and the emotional state of family members, especially in terms of the mothers of these children. However the current finding does not concur with the relationship of the family when the sick child is emotionally withdrawn. The study findings found that even within the family and extended the relationship is either positive or negative. However the study concurs with Belinda, Heatler, Ruth and Susan

(2010) who concluded that their findings support previous research with African-American families and expand their views of the importance of educating parents, family members, and others about sickle cell disease. They also suggest a need to explore sibling perception of this communication, parent and sibling perception of the impact of frequent hospitalizations and clinic visits on the sibling and family, and variations within families of children with sickle cell disease. The study also concurs with Vieira et al,. (2018) who posit that the relatives had divergent opinions about what this pathology would be and expressed the expectation of being broadly guided, from general information (signs and symptoms) to more complex ones about the disease, including major complications and ways of preventing them.

The study also wanted to find out the kind of food that parents give their child to maintain the life so that she/he can continue to access education. The study established that parents give a variety of diet contents while some parents are not keen on food given to the child to enable him/her access education. The parents reported as indicated below:

The boy just feeds on common foods like vegetables, eggs and fish. (P 7)

I give the son dagaa "omena", fish, fresh milk, tomatoes, onions, normal ugali, pumpkins, pumkin leaves, traditional vegetables, sim sim, sugar cane, spinach "blood booster" and other foods rich in starch and mushroom. (P 13)

My child feeds on different types of fish, butternut, fresh milk, "ododo" (traditional vegetable), rice, cassava, yam, beans, green grams, cow piece, "dek akeyo", "osuga" (traditional vegetables) and brown bread. (P 14)

I include Irish potatoes, mushroom for immunity, and beetroot which is good for blood level

Other forms of vegetable I use are like muringa leaves and nderma (traditional vegetable) (P6)

I really prefer to feed the child on the vegetables I use spinach and yam, we use beetroot which is a blood booster. (P 11).

The study agreed with Moore (2020) who identified foods that were similar to what the study found such rainbow fruits and vegetables and pair them with grains, and proteins (such as eggs, fish, chicken, meats, beans or tofu and nuts or seeds. Getting plenty of calcium-rich foods and beverages such as milk, yogurt, and cheese. Other sources of calcium include leafy green vegetables and calcium-fortified products such as soymilk and tofu, as well as some types of breakfast cereals and 100% fruit juices. Provide nutrient-rich, high-energy foods including dried fruit, nuts and nut butters, or smoothies if your child doesn't have much of an appetite. Sauces, gravies and sources of fat may also be added to meals and snacks for extra calories. The findings also concurs with Umeakunne and Hibbert (2019) who observed that interest in natural products is gaining attention as an integrative approach to management of sickle cell disease. Many of these tropical plants are native to the countries where high rates of sickle cell disease exist. Derivatives from plants have been shown to contain antioxidant properties from bioactive components such as phytochemicals and flavanols. Exploration for the use of extracts from the tropical plant Moringa oleifera is in progress, to determine the antioxidant capacity in the treatment of oxidative stress in sickle cell disease. The findings also concurs with Shamard (2020) who commented that parents and healthcare professionals need to create a diet that will meet the daily recommended dietary that best supports their child's growth and overall health needs. A diet high in fruits, vegetables, whole grains, and legumes usually provides enough vitamins and nutrients to support the health needs of people with sickle cell anemia.

The findings do not fully concur with Nutrition Guide for Clinicians (2021) that reminded patients with sickle cell anemia that they have greater-than-average requirements for both calories and micronutrients. During sickle cell crises, energy intake can be especially poor. Children frequently hospitalized for SCD commonly show poor linear growth, lean body mass, and reduced fat-free mass.

For reasons that are poorly understood, many patients are deficient in essential micronutrients. A diet emphasizing fruits, vegetables, whole grains, and legumes will provide a greater proportion of essential nutrients than a typical Western diet, and appropriate supplementation (1-3 times the recommended intakes for most essential nutrients) can prevent deficiency and may decrease the likelihood of disease exacerbation.

The study also wanted to find out the kind of fruits the parents give their children in this condition. The study revealed that parents provide a variety of fruits to the children with this condition. This was the observation from one of the parents:

The child has been feeding on bananas, pawpaw, date fruit which boost energy blood and is normally got about 50 km from home but very expensive because it is normally bought in kilograms. (P 2)

This study concurs with Phelamei (2020) who observed that it's important to eat a variety of fruits, including apples, oranges, bananas, grapes, melon, berries, kiwi, plums, peach, etc. These fruits can provide similar vitamins, minerals and fibre as vegetables for people with sickle cell anemia. The study findings also concur with Oye (2019) who observed that eating fruits and vegetables has many health benefits. For example, pomegranates increase blood flow, and fruits and vegetables such as bananas and kale boost energy levels. These benefits are especially advantageous for people with sickle cell anemia. Increased blood flow reduces the chance of a sickle cell crisis, while more energy helps us to combat fatigue. It therefore reflects that good eating habits may even increase the lifespan of individuals with sickle cell disease. The findings does not concur with Boadu, Ohemeng and Renner (2019) who stated that consumption of fruits and green leafy vegetables rich in vitamin A among the children was low and this could account for the observed difference. However this may true in some regions and with diverse individuals with sickle cell anemia disease.

The study also wanted to establish the kind of porridge (uji) the parents give their children to maintain their body to be able to access education. The study found that parents give their children a variety of porridge which is balanced.

My child feeds on enriched porridge ingredients. These are mixtures of yam, amarantha, finger millet, dried cassava and rice. (P 3)

I feed my daughter on rich porridge made from finger millet, dried cassava, sim sim and dried pieces of dried potatoes. (P4)

The boy feeds on finger millet, mixed with maize and millet sometimes just normal uji.

Sometimes the boy feeds on finger millet cassava, green grams and ground nuts (P 6)

The study does not concur with Taiwo (2017) who observed that with good nutrition and a healthy lifestyle, I can assure you that having a crisis will be minimal as you drink plenty of water and eliminate stress, until next time, I wish you a happy health life without crises but did not specify the type of porridge an individual with sickle should feed on.

The study does not also not concur with Andago (2015) who stated that despite health and nutrition education talks that discourage mothers from including certain mixtures in porridge flour, such as beans and groundnuts, the practice is rampant. That good complementary foods are rich in energy, protein and micronutrients, especially iron, and are not watery (i.e. thick not thin porridges);

The study wanted to establish the experience of parents on taking care of the child in this condition to access education

Parents had their observations as noted:

Horrible, an expensive exercise. The two parents should understand one another from the beginning. It was and has been expensive caring for the daughter because the crisis is frequent

I started with malaria; we have to control mosquitoes with nets. The child is not exposed to hard work to experience stress at any level. We have to take the child to hospital, to be prescribed drugs like folic acid. It has been very expensive treating the child during crisis and buying for her the prescribed tablets she needs, very costly. (P5)

Well most of the parents need to get a lot of money to maintain about 60 to 80 children each month who visit our facility each month. Apart from that a parent must maintain the child with the required food.

(Health officer in a sub county hospital)

We have to monitor the life of the boy who is to join a medical college to do nursing. The boy could be sick at any time. We depended on the doctor's advice in every step including emergencies and water drip. Blood transfusion, treatment and all those are money. (P 7)

Medication is very expensive, we spend about Kshs. 3000 ,00 each month and now when the doctors are on strike we spend double and beyond the normal cost. The monthly requirements are high for treatment. (P 9)

The finding concurs with Bilenker, Weller, Shffer, Donver and Anderson (1998) who observed that children with SCA had mean expenditures 8.8 times the mean expenditures for all children in Washington State Medical Program (WSMP). There was wide variation in the annual expenditures among children with SCA; the most expensive 10% of children accounted for 56% of total expenditures.

The study does not concur with Hala, Karl, Lorraine, Dyson and MDyson (2008) who posit that gateway to education issues that is proffered by a clinical and psychological focus is one-dimensional. The focus is on educational non-attendance and relative failure, on physical and per formative differences that mark out such children from their peers, and on physical symptoms that frame the young person as passive and eternally vulnerable. In countries like Kenya with the current curriculum which is being faced out from preprimary to Grade 4 the mean performance is the end result for education.

The finding does not concur with Abid, Hassan, and Ahmed (2019) that school performance and cognitive function were significantly lower among patients with SCD than among their classmates, and school absence and the age of patients had a negative impact on school performance. These children can learn and compete well in school except that they do not regularly attend school.

The study intended to establish whether these children attended regular schools. It was established that the children mostly attend regular schools.

Parents observed that:

The child started regular ECD, closer to home and going on daily basis. I had to change. I had three children with similar conditions. The elder boy joined form one from a regular school but he was a sickler . He succumbed to death in form two in a regular secondary school. The other ones are also siclers but they are in regular schools. (P 1).

My child attended up to class 3 but could not take even a week before becoming sick. During this time he was being taken to hospital. Teachers were aware of the sickness , I was consulting with that is why teachers knew he was sick . Teachers did nothing, he was gaining nothing and because the cold morning , it was hard and during the attack he must be brought back. Teachers could inform us of the attack by sending any child to come and inform us. We could go on a bicycle and take him to the hospital. (P 2).

The child attended school in class 3 at a regular primary, the distance from home to school is about 200metres. The child normally went a lone except during crisis. (P4).

My child attends school always only when sick. He feels tired, went to secondary school. He still continues with is education to a local secondary school which is regular. (p8).

My daughter attended a local primary and a secondary school. The secondary is a mixed day secondary school. (P 9)

The findings does not concur with CDC (n.d.) observed that teachers should be talked to about a 504 plan or Individualized Education Plan (IEP). A 504 plan requires that a child with special healthcare needs (i.e., that limits one or more major life functions) be provided with ways to participate in general education programs. For example, in a 504 plan, students and families may develop a written request for access to an extra set of books for home, more frequent bathroom breaks, access to water throughout the school day, or the need for extra layers of clothing.

The findings does not concur with UPMC (2021) stating that participation in school and peer groups are important for development of self-esteem during school years. Striving for independence can pose special challenges. Most of students with sickle cell disease are not provided with IEP for close assistance.

The study wanted to establish where the children learn whether it is a day, boarding or integrated school. Most of these children learnt in regular primary and private both day and mixed day secondary school.

The parents observed:

My child attended local school mostly day and mixed day. (P7).

The findings concur with Sickle Cell Disease News (n.d.) that children with sickle cell anemia do not have learning difficulties, but fatigue and recurrent pain can influence their ability to concentrate in school. They are also more frequently absent from school compared to other children because they must attend doctors' appointments or because they are having painful episodes. Children with sickle cell anemia, therefore, may require extra help or adaptations to the usual school routine. However in Kenya these children are not put in IEP program but can be given remedial work at the discretion of the teacher. Parents consult with the teachers to understand students' condition so that they can give them extra time.

The study wanted to establish who pays and any other levy in the school. The study established that both parents are responsible for fees and any other levy payment.

I'm paying school fees, but the mother also pays at times both of us are paying the school fees and levy. (P3).

I pay school levies despite my child being irregular in school due to health problems. (P15) .

The findings concur with Makori, Chepching, Misoi and Kiplagat (2015) who stated that cost sharing policy is a worldwide phenomenon affecting both developed and developing countries. In developing countries it affects all levels of education. The parents supplement the government efforts for all children to access education as it affects Kenya government currently. The findings do not concur with Morogo, Kirop and Too who in their study concluded that non- payment of school levies by parents was a critical threat to school programmes and projects. In the current study it was found that parents share the responsibility of paying school fees and any other levy in school for their child.

Teachers maintain open communication with parents. Teachers can help create a positive relationship between home and school as well as a sense of continuity for students by maintaining open communication with a child's family through notes, e-mail, phone contact or conferences to discuss the student's performance and well-being in the classroom and at home. Regular contact with a student's parents is especially important for children with a chronic illness, like SCD. Some children with SCD will have periods.

Tips for supporting students with sickle cell.

https://www.cdc.gov/ncbddd/sicklecell/documents/tipsheet_supporting_students_with_scd.pdf

The study intended to establish the awareness of parents on the rights of the child to access education. The parents are aware of the rights of the child rights to access education however this may be interfered with by crisis,

The parents revealed that:

I'm aware of that they should access education. You can't keep the child in the house. I know that there is education for all. As a parent it is my responsibility to assist the child to access education and try all my efforts to help him to access education without discrimination. (P 1)

The child should go to school but he was sick, my mother told us that her grand child should leave school. The ever crisis, the child stopped going to school. (P2)

I'm aware education is the key even without employment is power in information, however it is not easy with hospital and bills and admissions to the hospital frequently and going to school. Most of the time the boy is not feeling well. The condition is very difficult to manage. Even doctors used to remind the boy that from the hospital the child should go to school. His condition was also known by the doctors. (P7)

The study concurs with Hoyt, Abel, Lindsey and King (2014) who stated that children with SCD face more environmental challenges than most. Many children who suffer the physical effects of SCD also live in dangerous, impoverished neighborhoods and have limited access to educational opportunities This is likely to affect school attendance of individuals with sickle cell anemia.

https://bmcpublichealth.biomedcentral.com/articles/10.1186/1471-2458-14-116

The study findings also concurs with Abuateye, Arkin, Culley, Dyson and Dyson (2008) who observed that more broadly, regular school participation is seen as essential to children's education and social development as well as their psychosocial wellbeing (Fowler et al, 1986; Nash, 1989; Midence and Elander, 1994; Fuggle et al, 1996), but there is little substantial research that explores these issues in detail. Interruption to schooling and peer relationships is a particular difficulty facing children with a chronic illness (Mador and Smith, 1989; Davis and Wasserman, 1992; Shapiro et al, 1995; Wjst et al, 1996; Darr et al, 2005), and indeed the onset of painful crises or other clinical complications can disrupt education for those with SCD (Noll et al, 1996; Schatz et al, 2001; Koontz et al, 2004). Children with SCD may have restrictions placed on their physical activities and commonly experience fatigue that can make it difficult physically to keep up with peers (Noll et al, 1996).

School activities can be further limited by hospitalization, clinic visits or restrictions imposed by the expectations of others (Nettles, 1994) This therefore reflect that education for children with sickle cell anemia disease is known as a right as other children.

Education and Young People with Sickle Cell Disorder; A Knowledge Review https://diversityhealthcare.imedpub.com/education-and-young-people-with-sickle-cell-disorder-a-knowledge-review.php?aid=2153

The study also wanted to determine how the parents deal with weather changes during school days, to continue with school. The study found that parents use various methods to deal with weather changes for their child to continue accessing education.

The parents observed that:

Depending on weather changes, my child used to dress appropriately. During the cold weather that is normally part of the trigger crisis. The child put on sweater (pull over jacket), movin ,(sweater cap) sweater gloves and light shoes for example rubber shoes. (p14)

The study did not concur with Manwani (2016) who advised individuals with sickle cell anemia to remember, being practical about guarding against the combination of cold and wet weather can go a long way in preventing a sickle cell crisis during the winter months. In East Africa within the tropic the temperature is generally high except during the rainy season as such they don't experience winters. Winter months can pose a major health challenge for people with this inherited blood condition The findings concur with Miller (2018) who reminded parents to help their child avoid pain crisis triggers, such as extreme temperatures or stress. Most of the parents tried to keep their children as warm as possible to reduce the recurrent crisis.

https://kidshealth.org/en/parents/sickle-cell-anemia.htmlHealthwise The finding also concurs with May Staff (2020) who reminded individuals with sickle cell anemia to stay warm, exposure to cold air, wind, and water can trigger a sickle cell crisis. Dress children in warm layers of clothing for cold-weather activities. Avoid swimming and playing in cold water

https://www.mottchildren.org/health-library/uh1427

The study intended to establish how the parents manage sickle cell crisis to enable their children to continue accessing education. The study found out that parents approach this differently. Most parents use first aid with medicine from hospital or rush to the hospital while others also use traditional herbs during this condition.

The parents revealed the following:

The child is given warm water with tangawizi, warm water and lemon juice. Take martino scam (traditional medicine) 3 times a day depending on the recommended dose per day. I use pain killers for example dyclofenac, panadol or any other pain killer that the child always take . Put on warm clothes. When pain persist take the child to the hospital. (P 15)

Most parents collect martino scam. It can be stored under water in normal temperature, it is boiled every 3rd day. The top is covered with a clean cloth, the dosage is taken in small quantities for example 2 years and below take small quantity, 3-4 years take ¼ of a glass, 5-7 years take ½ a glass, 8-9 years take ¾ a glass and 10 year sand above take 1 glass in the morning and evening except when there is a crisis where it is taken 3 times a day, while if pain persist , the child is taken to the hospital. (p 8)

The study findings does not concur with Levy, Watson and Turley, (2021) who reminded the parent of children with sickle cell anemia to be careful about certain exposures that may trigger a crisis for their child. These include: High altitudes, Cold weather, Swimming in cold water help their child prevent infections by: Staying away from people who are sick, Washing his or her hands often, Having all advised vaccines such as pneumococcal, Having all advised screenings such as hepatitis. Some of the informants were using modern and traditional medicine. Chttps://www.urmc.rochester.edu/encyclopedia/content.aspx?ContentTypeID=90&ContentID=P02327. The findings also concur with Health Encyclopedia (n.d.) that reminded parents of children with sickle cell disease that the disease will sometimes have pain episodes. Talk with their child's healthcare provider about the best ways to handle these episodes at home. It may be appropriate to give the child pain-relieving medicines like ibuprofen for mild episodes or stronger pain relievers for more severe flare- ups. Heating pads, warm baths, and massage may also be soothing. The finding also agrees with who Drury, (2019) who reminded the parents to apply warmth to the painful area using a hot water bottle or deep heat cream, Massaging the painful area, deep breathing exercises, keeping a supply of painkillers, like acetaminophen (paracetamol), on hand. Parents struggle with their children with sickle anemia disease to access education by try all ways possible.

The study was also interested in knowing how sickle cell is generally managed so that the child can continue with learning. The study established that most parents use Martino scam (traditional medicine) , they could also take the child to the hospital.

One of the parents also observed that:

As the child grows, I try to use both the hospital and traditional medicine. I depend so much on the hospital personnel relieve pain for the child to go to school. (p 4)

The study concurs with McGann, Nero and Ware (2015) that proper management of sickle cell anemia (SCA) begins with establishing the correct diagnosis early in life, ideally during the newborn period. The identification of affected infants by neonatal screening programs allows early initiation of prophylactic penicillin and pneumococcal immunizations, which help prevent overwhelming sepsis. Most of the parents used hospital although some parents used traditional medicine. However the findings don't concur with Adewoyin (2015) who posit that simple steps that people with SCD can take to help prevent and reduce the number of pain crises, including the following: Drink plenty of water. Try not to get too hot or too cold.

Try to avoid places or situations that cause exposure to high altitudes (for example, flying, mountain climbing, or cities with a high altitude). The study found that parents were not keen on issues management as expressed by Adewoyin as they only focused on hospital and use herbal to manage the condition. The study For sickle cell crisis, when the severity of the episode is assessable, self-treatment at home with bed rest, oral analgesia, and hydration is possible. Individuals with SCD often present to the emergency department (ED) after self-treatment fails

The study concurs with Maakaron (2021) which can possible when parents who rush to hospitals in Kenya they may be advised to take folic acid supplements daily, and have a healthy diet drink plenty of water, avoid temperature extremes and exercise regularly, but don't overdo it.

The study intended to establish from parents how they manage their children generally to improve their school attendance. The study found that parents use varied methods including caring not to inflict pain on the child, avoiding strenuous work, counseling, checking on the attire of the child and encouraging the child to work hard.

Some of the parents had this to share:

I avoid inflicting pain (no corporal) punishment but try to counsel and reason with the son. I also make sure that the son, don't stay hungry at home or in school. I rule on verbal abuse bring him closer to God. (P 7)

I normally check on the attire of the daughter, I don't allow her to go to school bare footed or walk to school or walk in the home bare footed. I treat any sickness quickly. Prolonged pain can lead to crisis. I attend sickle cell day, join with other parents and learn from them. (P3), parents, patients, and providers to understand and manage the impact of SCD on school attendance is recommended The study does not concur with Schwartz, Radcliffe and Barakat (2019) who observed that school absenteeism is a significant problem for adolescents with SCD despite the presence of academic goals. Collaboration between schools. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2684846/

The study does not concur with WWC (n.d.) that parents to set up a meeting to discuss SCD with his/her child's teacher. It may be important for parents and teachers to meet at the beginning of each school year. However it is not practical in this country for parents to have a meeting with teaching staff about the child's health conditions.

The study does not concur with Lola Oni (2013) who reported that sickle cell disease may affect your child's educational progress. This may be because he is frequently unwell and has to miss school. Children may suffer from stroke and this may affect their learning ability and their behaviour. Most participants from the study did no report conditions of stroke however the participants revealed how they are taking care of their children during school to avoid the advent of crisis and / episodes that may lead to absenteeism in school.

The study intended to establish the experience of parents on the education of their children with this condition. The parents revealed that educating is very expensive.

One of the parents observed that education is expensive. I first took the child to a regular school but the child dropped. I later took the child to a boarding school, there is no strenuous work but I have set money for transport during his attendance of regular school. During crisis the child have to leave school. The child sometimes misses exams and have to repeat class. Feeding program in the school I have to supplement what the school offers. I had to set aside Kshs.100.00. when the child was in regular day school while other children who are not sicklers do not incur such expenditures. (p 7)

Majority of these children are exceptional they are good. The two of my children are above average. Teachers don't understand them. Teachers treat them the same way. Children with disability may feel overprotected. Most teachers are ignorant. They blame parents of not taking care of their children yet educating these children is very expensive. (P 1)

The study concurs with Raeda and Abdel (2017) observing that those parents of children with sickle cell disease face complex care giving demands and altered family dynamics that warrant careful assessment and attention by the healthcare providers. However, the study does not concur with Karadag, Zeynep and Zeynep (2018) that families may experience feelings such as guilt, helplessness, anxiety and anger, and they may have difficulty in coping with these negative feelings induced by caregiver responsibilities although it was noted that parents face frequent hospitalization of children, economic burdens caused by medical expenses, and uncertainties about the future of their children.

The study also intended to find out how parents relate with the school administration. It was found that the relationship is good. The parents had the following observations:

I have to make the school know the condition of the child, what the child can do and cannot do . For me I explained the condition of the child. I inform them when the child is sick and is absent from school, they should know. They have our phone numbers to inform us when the child is in crisis to contact us to collect the child during emergency. Teachers are now positive they call my number immediately they realize the child has changed, they call us immediately (P10)

The relationship is good and the child is doing well in school. I informed the school when the child is admitted and when the child miss school. (P 11

The study findings does not concur with Cori, Naomi, Mary, Irwin, James, Lsa, Karen and Monica (2016) that the study findings indicated that participants with SCD were achieving average grades but their retention rate appeared to be higher than the national average. Some participants who perceived that SCD interfered with school performance were not receiving educational supports

https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4991639/ Google Scholar

The study concurs with Lisa, Jerilynn and Lamia (2009) who concluded that School absenteeism is a significant problem for adolescents with SCD despite the presence of academic goals. Collaboration between schools, parents, patients, and providers to understand and manage the impact of SCD on school attendance is recommended.

https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2684846/

The study intended to find out what parents think teachers should do to assist their sick children to improve their academic performance. The study found that teachers should encourage these learners to perform, counsel and to view life positively.

One of the parents revealed the following:

They should give extra teaching because the child loose a lot when absent. They should encourage the child not to despair since they view life as nothing. These children should be exempted from manual work and physical education and any other difficult exercise. They should play but be controlled. (P5)

The study concurs with SickKids staff (2011) which observed that students with SCD may miss school because of scheduled clinic visits inpatient, hospitalizations to treat the severe bone pain associated with SCD and less severe painful bone crises being treated at home. This means that they have less instructional time. It has been proven that school attendance is directly related to academic performance. A parent could speak with the child's teacher about setting up a homework buddy program for the whole class. Each student would have a "buddy" who would collect handouts and notify the absentee student of important future deadlines. Many teachers have websites where they post homework assignments and future dates for both parents and students. If these exist, please bring them to the attention of parents and students. However in Kenya, parents expect teachers to give children with sickle cell extra work to cover what was done in their absence when attending clinic or inpatient, may not work directly with teachers to ensure this is done. Most of the parents may not give children with sickle cell the needed academic support level because of low level of education, Kenya being a developing country. The study findings concur with the Editorial Team (2021) which suggested that to accommodate absences teachers should make-up assignments and instruction In addition, an individualized care plan should be written with input from teachers, nurses, your child, and the family.

The study wanted to find out how the parents maintain their children in school. The study found out that some parents earn some salary, while majority get wages from petty from juakali incomes. The parents have got following;

I earn little from job of most of it I use meet expenditures in school (p 8)

Little am getting juakali is what I use try meet the cost. (p 3)

Am only getting petty employment at certain period of year to meet

the expenditures in school. (p 9)

I pay little money meet expenditure at school. (p 12)

Children 'Health Qeenland Hospital and Health Services (n.d.) Managing sickle cell disease at schools

Participation at school and child care is key to building self-esteem and giving children a sense of belonging. It is important to maintain open communication with the family of a child with Sickle Cell Disease (SCD) so that they can thrive in these out-of-home environments. When teaching or caring for a child with SCD the following must be considered for the sake of their physical and emotional wellbeing. Accessed on 4th October 2023 from w.w.w.childrens.qld.gov.aus

Start preventive care as soon as your child is diagnosed, even if your child isn't yet having symptoms.

Find a qualified, patient-centered sickle cell care center to serve as a "medical home" for your child.

To reduce the risk of dangerous infections, your child should be receiving penicillin from the age of 2 months until at least 5 years old. Some children need it longer – or even throughout their lives.

Starting at 2 to 3 years of age and continuing until age 16, your child should get an annual transcranial Doppler test to assess stroke risk. Also, consider an MRI for your child beginning at age 5.

Seek medical attention promptly for symptoms such as fever and pain. They can indicate a serious problem.

Learn how to feel your child's spleen for enlargement, and check it regularly.

Make sure your child always stays hydrated.

Make sure your child eats a healthy diet.

Stay up to date on your child's immunizations.

Make sure your child takes all medications as prescribed.

Protect your child from exposure to extreme temperatures. For example, dress your child extra warmly on cold days.

Ensure your child receives proper medical attention at school and has a safe learning environment.

UCSF Benioff Children's Hospitals medical specialists have reviewed this information. It is for educational purposes only and is not intended to replace the advice of your child's doctor or other health care provider. We encourage you to discuss any questions or concerns you may have with your child's provider.

What challenges do you face in the education of the child?

Parents revealed several challenges they were facing in order manage the education of children in school. Some of the observations were as follows;

The cost of buying medicine was expensive and this frequent all the year round.

The meals that were required were very expensive.

Hospitals were far and cost of transport was expensive.

Episodes come most of the there was no money to hospital facility.

Stigma for the family and the child before society.

Emotional reactions in the child.

The cost counseling the parents and child was expensive.

What future plans do you have for your child after school?

The study also wanted to find out the future plans for child.

The parents had several observations as follows;

This my child at end of form iv the join medical services (p 3).

The child can join juakali (p 8).

The child can join teaching (p12).

The child can join artisans. (p 9)

However, most parents had little hope that their children might not have any future because of chronic sickness in life. Parents to parents need to encourage one another for wellbeing of their children to support them.

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