European Journal of Special Education Research
ISSN: 2501 - 2428
ISSN-L: 2501 - 2428
Available on-line at: www.oapub.org/edu

doi: 10.5281/zenodo.1227295 Volume 3 | Issue 3 | 2018

CHALLENGES FACED BY FAMILIES WITH SCD PATIENTS IN KOGI STATE, NIGERIA

Okpanachi, Monica Ojoma[1],
Agashi Pius Petinga[2]
[1]Kogi State College of Education, Ankpa, Nigeria
[2]Kogi State College of Education, Ankpa, Nigeria

Abstract:
The study sought to highlight the major challenges faced by families with Sickle Cell Disease (SCD) in Kogi State, Nigeria. It was excited by the need to have empirically documented evidence aimed at guiding the affected families in making necessary preparations for coping and adjustment. The study was conducted using a purposive sample of representatives from 70 families (one for each family) with SCD patients in Ankpa Area Council of Kogi State, Nigeria. The study was guided by 5 research questions and two null hypotheses. The instrument used for the study was questionnaire for families with sickle cell patients (QFSCP) which was constructed by the researchers on a 4-point Liker scale. QFSCP was face – validated by three experts in various disciplines. The reliability was calculated from data generated from a pilot study on 30 families with SCD patients using the Split half and Spearman Brown prophesy formula which resulted in reliability coefficient of 0.82.QFSCP was administered on members of 70 families with SCD patients (one from each family) with the aid of two assistants. Data generated were analyzed using mean for the research questions and chi-square for the hypothesis at 0.05 level of significance. Among other findings are: (I) Families with SCD patients are emotionally disturbed due to the enormousity of the pain. (II) Families with SCD patients need a lot of financial support as SCD is a high- cost intensive illness that continues throughout life. Based on the findings, some recommendations were made such as: (I) Government and care agencies should establish centers in hospitals and communities for SCD patients and their families where issues on challenges associated with the disease are handled. (II) Government and well spirited individual should endeavor to provide free treatment for SCD patients. This will ameliorate the financial burden of families with SCD patients.

Keywords: challenges, families with SCD, Kogi State, Nigeria

1. Introduction

In recent time, sickle cell anemia or sickle cell disease (SCD) has become one of the world's most dreaded and feared diseases that has remained a threat to families and individuals globally. SCD is a blood disorder that affects hemoglobin, the protein found in the red blood cells that help carry oxygen throughout the body (Hassel, 2010).

Sickle cell disease affects millions of people worldwide. It is most common among people whose ancestors come from Africa, Mediterranean countries such as Greece, Turkey, Italy, the Arabian Peninsula, Indian and Spanish speaking regions in the South America and parts of the Caribbean.

Brousseau, Owens, Mosso, Panepinto& Steiner, (2010) reported that sickle cell disease occurs more commonly among the people whose ancestors lived in tropical and sub-tropical, sub-Saharan regions where malaria is or was common, carrying a single sickle cell allele (sickle cell trait) confers a selective advantage. Fleming (1982) noted that there is some evidence that sickle cell anemia/disease has been recognized in Africa by black Africans long before the earliest description in the medical literature at the beginning of the twentieth century. Most of this evidence comes from Ghana (Konotey-Ahulu, 1974). Various ethnic groups in Ghana including the Twi, Ewe and Ga people identified SCD as an entity to the extent of pin-pointing some cardinal features such as recurrent attacks, of pain in the bones and joints, the variable severity of the disease and its familial tendency but with the parents of the affected children appearing normal.

In Nigeria, the largest black African nation, SCD remained unrecognized as a distinct disorder by the various ethnic groups until not too distant past when the symptom was discovered among families and individuals in the society. Sickle cell disease is a lifelong disease. It is a complex condition that affects the patient, the family and the patient's and family relationship with health care providers and the community (Vichinsky, 1991). SCD is one of the most common inherited diseases worldwide and pain is the most important symptom of the disease. Yuette (2014) described the pain as deep, gnawing and throbbing. The skin may be tender, red and warm in the painful areas.

The hallmark features of SCD is frequent and unpredictable pain termed Vaso-Occlussive Crisis, which account for approximately 25% of hospital visits in children with SCD.Vaso-Occlusive Crisis (VOCs) are the result of "sickling" of the blood vessels leading to lack of flexibility. Specifically, the red blood cells become sickle shaped and sticky blocking blood flow through the vessels which results in pain, ischemia and infarction (Ballas, 1998). The frequency of these pain episodes ranges from fewer than once a year to multiple times a day. Pediatric sickle cell patients experience pain on average of 4-5 days prior to admission. Also several diary studies with children and adolescents, noted VOCs ranged from 2-3 days within two to seven week period.

SCD is a huge stressor to which both the one afflicted with it as well as his/her family and friends will potentially have difficulties adjusting and coping with. As pain is a long standing complication in sickle cell disease, coping with pains and

employment of different strategies to cope has been shown to predict adjustment and severity of pain.

The challenges facing families with SCD is enormous and the management of the disease requires a comprehensive, multidisciplinary approach, and involves managing not only the patient but also the family as well as others who may be affected by patient's illness (Moskowitzetal, 2007; Holding & Heggdal, 2010). The components of comprehensive care as reported by Okpala (2004) include patient/parent information, genetic counseling, social services, prevention of infections, dietary advice and supplementation, psychotherapy, renal and other specialist medical care, maternal and child health, orthopedic and general surgery, pain control, physiotherapy, dental and eye care and others.

It is therefore obvious that both the SCD patient and their families have a lot of varying challenges to cope with. Some of these challenges have not been adequately documented for the purpose of guiding the affected families and making necessary preparation for coping and adjustments. This is more so in Nigeria especially at the local government level where there is acute dearth of documentation. This study is excited by the need to fill this documentation gap.

2. Statement of the Problem

SCD has been conceptualized as a disease with both psychosocial and physiological complication. Due to unpredictable, frequent and sometimes severe nature of SCD pain, coupled with its inconsistent response to intervention, SCD pain is a challenge for both clinicians and care givers to manage. Families in Ankpa Local Government Area of Kogi State with SCD patients face a lot of challenges on how to cope with the trauma. Crisis situations may be minimized by identifying specific points at which psychosocial interventions may be necessary and planning for them, thus eliminating the frustration and ineffectiveness often experienced by patients and care givers. Skills for coping with pains and other complications of SCD must be taught early and reinforced often. The desire to contribute to the pool of knowledge with regards to the challenges facing families with SCD patients excited this study. Providing patients/families with information is a key to helping them manage the pain

2.1 Purpose of the Study

The main purpose of the study is to establish the challenges faced by families with SCD patients. Specifically the study intends to find out the following:

1. To find out the emotional challenges of families associated with SCD.
2. To discover the financial challenges faced by families associated with SCD.
3. To examine the feeding challenges faced by families associated with SCD
4. To establish the academic challenges faced by families associated with SCD
5. To determine the stress challenges faced by families with SCD patients

2.2 Research Questions

The study is guided by the following Research Questions

1. What are the emotional challenges faced by families associated with SCD?
2. What are the financial challenges of families associated with SCD?
3. What are the feeding challenges of families associated with SCD?
4. What are the academic challenges faced by families with SCD patients?
5. What are the stress challenges of families with SCD patients?

2.3 Hypotheses

The following hypotheses guided the study:

1. The responses of families challenges faced patients with SCD are independent of their socio-economic status
2. The responses of families on the challenges of SCD are independent of their qualifications.

2.4 Significance of the study

The findings of the study will be of significance to families with SCD patients, individuals with SCD, health workers, teachers and researchers. For the individuals with SCD, as they get more enlightened on the challenges, strategies for coping with the conditions could be adopted. For health workers, they would have a document to refer to when helping those with SCD. For teachers, they will impact the lives of their affected students by giving them the right counsel concerning SCD. For researchers, they will have an existing pool of knowledge to draw from.

3. Method

3.1 Design of the Study

The survey research design was used for the study. The choice of this was considered relevant because it permits interaction with the objects of the study (i.e families of sickle cell patients) in their natural settings. According to Azuka (2011) survey research design is one in which data is collected and analyzed from a few people or items considered to be representative of the entire group.

3.2 Area of the Study

The study was carried out in Ankpa Local Government Area of Kogi State. Ankpa Area Council is one of the Area Councils of Kogi State and one of the 9 Area Councils in Kogi East Senatorial District of the state. It is bordered in the north by Omalla Area council of Kogi State, in the East and South by Benue State (of Nigeria) and in the West by Olamaboro Area Council of Kogi State.

3.3 Population of the Study

The population of the study consists of all families with sickle cell patients that were registered in the General Hospital, Ankpa which serves the whole local government area.

3.4 Sample

There were 70 sickle cell patients that registered with the General Hospital, Ankpa. A total of 70 parents (one for each patient) were used as purposive sample for the study.

3.5 Instrument for Data Collection

The instrument used for data collection is Questionnaire for Families with Sickle Cell Patients (QFSCP). It is constructed on a four point Linker Scale. QFSCP is divided into five main sections. Section A consists of two (2) items seeking information about the socio-economic status and the qualification of the respondents. Section B,C,D and E are made up of forty (40) items generated to address the five research questions.

3.6 Validation of Instrument

QFSCP was face validated by three experts in various disciplines. Two of the experts were from the Department of Vocational Teacher Education (VTE) University of Nigeria, Nsukka (UNN) and one from the Department of Guidance and Counseling, Kogi State College of Education, Ankpa. Their comments and suggestions bordered on the suitability of the items generated for the study, language and structural arrangement of items of the instrument. Their suggestions and recommendations were used to produce the final copy of the instrument.

3.7 Reliability

The reliability was calculated from data generated from a pilot study on 30 families with SCD patients, using Split-half and Spearman Brown Prophesy formula which yielded 0.82

3.8 Method of Data Analysis

The data generated for the study were analyzed using mean for the Research Questions and Chi – Square to test the hypotheses at 0.5 level of significance.

4. Analysis

The data generated were analyzed in the tables below according to the Research Questions and hypotheses.

Research Question 1: What are the emotional challenges faced by families with SCD patients?

Table 1: Emotional challenges faced by families with SCD patients

S/N	Items	SA	A	D	SD	Total	X
1	Families with SCD patients have sleepless night during the period of their patient's crises.	55	15	-	-	265	3.8
2	Families with SCD patients are often involved in transfer of aggression when dealing with people	12	24	19	5	163	2.3
3	Families with SCD patients often misunderstand themselves on account of their challenges	10	46	14	-	206	3.7
4	Families with SCD patients feel much pain to see their child going through extreme pain alone	50	20	-	-	260	3.7
5	Families with SCD patients often feel sad on account of their patient's painful condition.	48	15	7	-	251	3.6
6	Families with SCD patients need behavioural therapies that teach coping skills which will result in less negative thinking and possibly reduce the pain	48	15	7	-	251	3.6
7	Families with SCD need support groups who will advocate for their patients.	39	29	2	-	257	3.5
	Cluster Mean						3.8

From the table 1 above, the cluster mean is 3.8 while all the items have mean of above 2.5 except item 2 which has a mean of 2.3. Almost all the items pose emotional challenge to families with SCD patients

Research Question 2: What are the financial challenges faced by families with SCD patients?

Table 2: Financial challenges faced by families with SCD patients

S/N	Items	SA	A	D	SD	Total	X
8	Families with SCD patients often make special budget for treatment.	9	33	26	-	187	2.7
9	Families with SCD patients often borrow money for treatment and maintenance of their patients.	32	19	19	-	223	2.5
10	Families with SCD patients often receive neighborhood and charity organization's support	14	20	26	10	178	2.9
11	Families with SCD patients often find it difficult to launch into various income yielding ventures because of the physical care of their patients.	15	33	22	-	203	2.9
12	Families with SCD patients find it difficult to pay the school fees of their patients.	13	30	21	6	190	2.7
13	The standard of living of families with SCD patients is poor.	14	23	30	3	188	2.7
14	Families with SCD patients find it difficult to manage money because of the continuous demand of the ill-health	43	11	2	209	3.0	
	Cluster Mean						2.7

From table 2 above, the cluster mean is 2.7. All the items have means of 2.5 and above. This means that all the items pose financial challenges with SCD patients.

Research Question 3: What are the feeding challenges associated with SCD?

Table 3: Feeding challenges associated with SCD

S/N	Items	SA	A	D	SD	Total	X
15	ScD patients go on expensive diets	10	36	19	5	191	2.7
16	SCD patients go on normal diets	2	24	34	10	158	2.3
17	SCD patients eat more often	4	9	50	7	150	2.1
18	SCD patients have poor appetite	12	15	35	8	171	2.4
19	SCD patients have low weight status for their age	37	29	4	-	243	3.5
20	SCD patients go on vitamins and mineral supplement	48	18	1	3	251	3.6
21	SCD patients need plenty of fluids	15	52	2	1	221	3.1
22	SCD patients need a lot of fruits and vegetables	50	19	1	-	258	3.7
23	SCD patients need nutritional interventions	40	30	-	-	250	3.6
24	Families with SCD patients need nutritional education/counseling	40	30	-	-	250	3.6
	Cluster Mean						**3.1**

Table 3 above has a cluster mean of 3.1. Items 15,19-24 have means of above 2.5 while items 16, 17 and 18 have means below 2.5. More than half of the items constitute feeding challenges faced by SCD patients.

Research Question 4: What are the academic challenges faced by SCD patients?

Table 4: Academic challenges faced by SCD patients

S/N	Items	SA	A	D	SD	Total	X
25	SCD Patients are often absent from school	36	30	1	3	237	3.4
26	SCD patients perform well in the school	7	37	16	10	181	2.6
27	SCD patients graduate on schedule with their peers	1	19	25	25	136	1.9
28	SCD patients often need extra lessons from their teachers	12	46	12	-	210	3.0
29	SCD patients are always late to school	8	18	42	2	172	2.4
30	SCD patients are afraid to face examinations	11	6	47	6	100	1.4
31	SCD patients cannot cope academically	10	14	39	7	167	2.3
32	SCD patients need scholarship award scholarship award to cater for their academics	25	32	9	4	218	3.1
	Cluster Mean						**2.5**

Table 4 above has a cluster mean of 2.5. Items 25, 26,28 and 32 have means above 2.5 while others have means below 2.5. Four of the items constitute academic challenges faced by SCD patients.

Research Question 5: What are the stress challenges of families with SCD patients.

Table 5: Stress challenges of families with SCD patients

S/N	ITEMS	SA	A	D	SD	TOTAL	X
33	Constant heating of water for bathing, and massaging often puts families with SCD patients under stress	8	15	37	10	161	2.3
34	Frequent hospitalization of SCD patients always put their families under stress	28	40	1	1	235	3.4
35	Daily administration of drugs to SCD patients put their families under stress	6	25	33	6	171	2.4
36	Intermittent sleepless nights during SCD crises puts their families under stress	37	31	2	-	245	3.5
37	Families with SCD patients are always under stress of not knowing when their crises will occur	30	39	1	-	239	3.4
38	Families with SCD patients are always burdened with the stress of the fear of death	25	45	-	-	239	3.4
39	The fact that SCD is a lifelong disease put their families under continual stress	25	26	9	-	226	3.2
40	Families of SCD patients often fall sick as a result of much stress during their patient's period of crises	8	34	28	-	190	2.7
	Cluster Mean						**3.0**

The cluster mean for table 5 above is 3.0. Majority of the items have means of above 2.5 while only 2 items have means below 2.5. This means that stress poses a big challenge on families with SCD patients.

Table 6: X^2 Table for Hypothesis 1

Classes	No	Df	X^2Crit	X^2Cal	Remark
N18,000 & below	10				
N 19,000 – N50,000	19	9	16.92	0.7	NS
N 51,000 – N100,000	13				
Above N 100,000	28				

NS = Not Significant

From table 6, X^2cal ,<X^2crit, so the null hypothesis is not rejected; that is, the responses of families on the challenges of SCD are independent of their socio-economic status.

Table 7: X2 Table for Hypothesis 2

Classes	No	Df	X^2Crit	X^2Cal	Remark
SSCE	27				
NCE/HND	27	9	16.92	4.81	NS
First Degree	8				
Higher Degree	8				

NS = Not Significant

From table 7, X^2_{cat}< X2crit, so the null hypothesis is not rejected; that is, the responses of families on the challenges of SCD are independent of their Qualifications.

5. Summary of Findings

The following are the findings of the study:

1. Emotional challenge is one of the major findings of the study. Parents with SCD patients are emotionally disturbed due to the enormousity of the pain.
2. SCD is a high cost intensive illness that continues throughout one's life. Families with SCD patients need a lot of financial support.
3. Nutritional intervention four SCD patients cannot be over emphasized. Families with SCD patients need to provide adequate diet to meet their patients' needs as a result of continuous ill health.
4. SCD patients are always in and out of the hospital as a result of their ill health; this might affect the academic standard of the parent concerned.
5. SCD is a lifelong disease; this puts the whole family under serious stress as everybody in the family will be involved during the crises.

6. Discussion of Results

The discussion is based on the findings from the study. The emotional changes faced by family with SCD patients ranges from sleepless nights during the period of their patients crises, transfer of aggression when dealing with people, misunderstanding of themselves on account of their challenges, feeling much pain to see their child go through extreme pain alone, feeling sad on account of their patients painful condition, needing of behavioural therapies that teach people copying skills to reduce pain, need of support groups that will advocate for their patients. This agrees with Halding and Heggdnal (2010) who reported that the burden of the diseases can affect all aspects of the lives of the individuals /families which include physiological, psychological and social wellbeing. Furthermore, the finding agrees with Fuggie and Davies (1993), who reported that emotional challenges contribute to feelings of hopelessness, helplessness and frustration.

Financial challenges of families with SCD patients are enormous; families that are well to do will need special budget for treatment as the crises can start at any time. The less privileged families would often borrow money for treatment and maintenance of their patients. Some might receive help from neighborhood and charity organizations.

Dietary challenges faced by families with SCD patients are huge. Most of the items on table 3 constitute feeding challenges. Adequate nutrition and hydration is very crucial for SCD patients. This agrees with the report of Moskowit Z. et al (2007) that care givers are tasked with responsibility of managing SCD parents which include providing adequate nutrition/hydration. Also, Studlrt & Nugel, (2004) reported that drinking a lot of fluids is mandatory for SCD patients.

SCD patients often experience academic challenges. Due to the facts that SCD parents are always in and out of hospitals, one would expect that they might have problem of irregular attendance in schools and so might not cope academically.

SCD is a huge stressor. All the items in table 5 constitute stress challenges. With respect to the family, care givers of children with SCD are burdened with missed work, increased family stress and increased care demand which is due to the unpredictability of pain crises, care in SCD (Moskowitz et al, 2007).

Table 6 reveals that the challenges of families with SCD patients have nothing to do with their socio-economic status. Put in another way, the level of income of families with SCD patients does not mitigate the emotional, academic, stress and other challenges the families go through. This gives credence to the popular saying that the rich also cry: With SCD, the agonies of families of high income earners are comparable to the agonies of families with low income earners.

Table 7 reveals that the null hypothesis is rejected; that is, the challenges of families with SCD patients have nothing to do with their Qualifications. This also shows that with SCD, the agonies of families of high education are comparable to the agonies of families of lower education. Agonies of families with SCD are no respecter of level of education.

6. Conclusion

There is a popular saying that "*To be fore-warned is to be fore-armed*". The findings of the study can serve as warning alert to families with SCD patients who can go a long way in making the necessary preparation and adjustments. It is hoped that Government and care-givers will also find the findings useful in making the necessary provisions to ameliorate the challenges confronting families with SCD patients.

6.1 Recommendations

Based on the findings of the study, the following recommendations are suggested:

1. Government should establish counseling centres in the hospitals and communities for SCD patients/families with SCD patients where issues on challenges associated with the disease are handled.
2. Government and well spirited individuals should endeavor to provide free treatment for patients suffering from SCD. This would take care of financial challenges by families with SCD patients
3. Teachers should be empathic towards students with SCD by paying more attention to them in their academic endeavours.
4. Government should provide food supplements for SCD patients. This will enable them to have access to balanced diet.

References

1. Ballas S.K. (2005): Pain Management of Sickle Cell Diseases, *Haematology/Oncology Clinics of North America*, 19:785-802,v

2. Brousseau, D.C., Owens, P. L., Mosso, A.L., Panepinto into, J.A., Steiner, C.A., (2010)., Acute Care Utilization and re-hospitalization for Sickle Cell Disease. JAMA, 303 (3) 1288-1294.
3. Fleming, A.F. 1982): Sickle Cell Disease. London: Churchill Livingstone Publishers.
4. Hahn, E.V. & Gillespie, E.B (1927): Sickle Cell Anaemia, *Archives of Internal Medicine*, 39,233-254
5. Halding, A.G, Heggdal, K (2010): Experience of Self-blame and Stigmatization for Self-infliction among Individuals Living with SCD, *Scand, Caring, Sci*. May 31 (Pub. Med).
6. Hassle, K.L. (2010). Population Estimates of Sickle Cell Disease in the U.S. *AMJ Prev. Med (sup/4*) S 512-S5521
7. Konotey-Ahulu, F.I.D (1974): The Sickle Cell Diseases: Clinical Manifestations Including the "Sickle Crisis". *Archives of Internal Medicine*, 133,611,619.
8. Midence, K., Fuggle, P. & Davies, S.C. (1993): Psychological Aspects of Sickle Cell Diseases in Childhood and Adolescence: A Review: *British Journal of Clinical Psychology*, 32
9. Moskowitz, J.T., Butensky, E., Hamarth, P., Vichisky, E. Heyman, M. B, Acree, M. et al (2007): Care giving Time in Sickle Cell Diseases: Psychological Effect in Material Caregivers. *Pediatric Blood Cancer*, 48, 64-71
10. Vichinsky Z.P. (1991): Comprehensive Cure in Sickle Cell Disease. It's Impact on Morbidity and Mentality. *SeminHemutol* 28:220 – 6.
11. Yuethe, C.T, (2014): Sickle Cell Diseases: managing the Pain, *Published Online*, Friday, Sept. 12,2014