



## Parental Influence on Sickle Cell Crisis among Patients Attending Secondary Facilities in Abeokuta South Local Government Area, Ogun State

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### Authors' contributions

This work was carried out in collaboration between all authors. Author ABJ designed the study and wrote the protocol. Author OEA analysed the study and wrote the manuscript. Author ADA managed the literature searches. All authors read and approved the final manuscript.

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### ABSTRACT

**Introduction:** Sickle Cell Disease (SCD), the most common genetic disorder amongst Black people and one of the major chronic non-communicable diseases (NCD) affecting children, poses a significant psychosocial burden, not only on the sufferers but also on the parents. This study therefore sets out to assess the influence of these parents' knowledge and practices towards reducing the frequency and seeking appropriate treatment of Sickle Cell Crisis in their children.

**Methodology:** This study is a descriptive cross-sectional study conducted in Abeokuta South Local Government Area. A Total Sampling of all the sickle cell patients that attend the selected facilities were recruited into the study. Data were collected with the use of questionnaires which were interviewer administered. Statistical analyses were conducted using SPSS for Windows version 20.0.

**Results:** A total of 415 patients were recruited into the study. Only 39.0% had adequate knowledge of SCD, 75.2% on prevention of crisis and 62.0% on predisposing factors to sickle cell crisis. About two-third [68.0%] of participants' source of information is by hospital staffs. Majority 81.4% have

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only one child with SCD. The frequency of sickle cell crisis was statistically significantly associated with the Marital status of the parents [ $\chi^2 = 24.029$ ,  $p = 0.0001$ ], Parents level of education  $\chi^2 = 18.538$ ,  $p = 0.0001$ , and the source of parents information about SCD  $\chi^2 = 18.194$  and  $P = 0.001$ . On logistic regression analysis, predictors of low frequency of crisis were individuals who had parents with tertiary education [OR=2.37, CI=1.45-3.87], information from health workers [OR=0.58, C.I=0.43-0.79], and family income above minimum wage [OR=0.147, C.I=0.06-0.34].

**Conclusion:** The study reveals that the level of care and support given to SCD children may reflect in their parent's level of education, depth of knowledge about the disease and financial capability, therefore attention to the psychosocial problems of parents and/or caregivers of these children is of utmost importance.

*Keywords: Sickle cell crisis; parental influence; secondary facilities; Ogun State; Nigeria.*

## 1. INTRODUCTION

Sickle Cell Disease (SCD), the most common genetic disorder amongst Black people and one of the major chronic non-communicable diseases (NCD) affecting children, poses a significant psychosocial burden, not only on the sufferers but also on the parents [1]. About 5% of world's population carries the gene responsible for haemoglobin disorders and about 300,000 infants are born worldwide with sickle cell disease every year with 200,000 infants born in Africa [1]. The impact on the parent is worse in developing countries because of inadequate social welfare and health care services. Within the family micro-environment, children with SCD need optimal family support, understanding and care, particularly in terms of providing adequate nutrition and health care delivery so as to achieve an optimum and steady state of health. This will help in reducing the frequency of Crisis and proper management of their children when they have crisis. Such favourable family environment has been shown to be a good prognostic index [1,2].

It has been established that about 24% of the entire population of Nigeria or 1 in 4 Nigerian men and women are healthy carriers of the sickle cell trait. Consequently, the population of Nigerians who are healthy carriers of the sickle cell trait (Hb AS) are about 40 million. This number far exceeds the total population of every other affected African country and indeed of several of them put together. Nigeria, therefore, has the largest sickle cell gene pool in the world [3,4]. About 2% of all babies born to Nigerian parents have sickle cell anaemia. Two per hundred births translates to over 150,000 births annually of children with sickle cell anaemia. This is very high when compared to the incidence of other serious inherited disorders that are commonly found in other races.

In Africa, cultural factors are particularly relevant to these problems because of beliefs and traditional practices which are usually influenced by cultural and religious values that influence health behaviours such as coping strategies. Studies have shown that a child affected by SCD is often a shock for the parents no matter how well prepared the parents may have felt. Families that have children with sickle cell disease (SCD) endure numerous potentially stressful experiences and daily hassles related to the biological complications of SCD [5-7]. These ordeals can cause difficulties with finances, work, transportation and changes to daily routines. Mothers of children with SCD are at risk for excessive anxiety, depressed mood, guilt, social isolation and personal health problems. Psychosocial issues for people with SCD and their families mainly result from the impact of pain and symptoms on their daily lives and society's attitudes to SCD and those affected. The initial hurdle of accepting the diagnosis is often quite difficult and parents may experience the initial emotion of denial [5]. Other common emotions include anger, fear and even grief. Sometimes there is an overwhelming sense of frustration, the blame of self and also of partners and feelings of inadequacies are not uncommon but for the majority of parents, these are transient emotions but others never come to terms with the fact that their offspring is affected by SCD [6].

Environmental and social factors are major influences on the parents' ability to cope and these have far reaching implications affecting the child in all aspects of his or her development. Parents with little or no support, living in unsuitable accommodation would perhaps find it more difficult to cope with an affected child more so than those parents who are well supported and are not experiencing hardship [8-11].

In Nigeria and other African countries, there is no doubt that the prevalence of the condition is increasing, especially among the urban educated elite and in other communities with or without access to effective basic health care. There is however, a palpable lack of attention to the plight of the parents of children with the disorder within our communities [9,10]. This, with the increasing prevalence, has encouraged the growth of myths, misinformation, inappropriate treatment, frustration and stigmatisation. The frustration has kindled the desire in many Africans to do something about sickle cell disorder. This study therefore sets out to assess the influence of these parents' knowledge and practices towards reducing the frequency and seeking appropriate treatment of Sickle Cell Crisis in their children.

## **2. METHODOLOGY**

### **2.1 Study Location and Population**

Abeokuta South is a Local Government Area in Ogun State, Nigeria. It was established in 1991 and mainly inhabited by the Egbas, who are of Egba Eku, Egba Aarin and Egba Igbeyin. The headquarters of the LGA are at Ake Abeokuta 7°09'00"N 3°21'00"E. It has an area of 71 km<sup>2</sup> and a population of 250,278 at the 2006 census. The Local Government shares border with Odede LGA on its North frontier, Obafemi/Owode on the Eastern while Abeokuta North LGA on the Southern part respectively. The postal code of the area is 110.

Abeokuta South LGA lies in fertile country of wooded Savanna, the surface of which is broken by masses of grey granite. It is spread over an extensive area, being surrounded by mud walls 18 miles in extent. Palm-oil, timber, rubber, yams, rice, cassava, maize, cotton, other fruits, and shear butter are the chief articles of trade. It is a key export location for cocoa, palm products, fruit, and kola nuts. Both rice and cotton were introduced by the missionaries in the 1850s and have become integral parts of the economy, along with the dye indigo. It lies below the Olumo Rock, home to several caves and shrines. The town depends on the Oyan River Dam for its water supply, which is not always dependable.

The Local Government is divided into 15 wards for the purpose of electing councillors into the Local Government Council. Each electoral Wards has primary Health Centre, Private Clinics, Laboratories, Pharmacy Shops, and

Traditional Birth Attendants. Also located in Abeokuta South LGA is State Hospital Sokenu which is a Secondary Health Centre. Abeokuta is the headquarters of the Federal Ogun-Oshin River Basin Authority, which is responsible for development of land and water resources for Lagos, Ogun, and Oyo states. Included in this are irrigation, food-processing, and electrification. Local industries include but are not limited to fruit canning plants, plastics, breweries, sawmills, and an aluminium products factory. South of town are the Aro Granite Quarries.

### **2.2 Study Design**

This study is a descriptive cross-sectional study to describe the Parental influence (socio-demographic characteristics, parent's knowledge, attitude and practice) on frequency of Sickle Cell Crisis among sickle cell patient in Abeokuta south Local Government Area.

#### **2.2.1 Setting**

This study was conducted in State Hospital Sokenu, Abeokuta and Egba Medical Centre, Isabo, Abeokuta both in Abeokuta South Local Government Area. The two hospitals hosts the two major sickle cell treatment centre in Abeokuta South LGA, Ogun State.

### **2.3 Sampling Technique**

A Total Sampling of all the parents of sickle cell patients that attend the selected facilities was recruited into the study.

#### **2.3.1 Sample size determination**

The minimum number of subjects required for the study is calculated using the formula:

$$\text{Minimum sample size, } n = Z^2 p q/d^2$$

Where Z is the standard deviation set at 1.96 at 95% confidence interval, p = prevalence set at 50%, q = 1-p, and d = degree of accuracy set at 0.05

$$n = Z^2 pq/d^2$$

$$= \frac{1.96^2 \times 0.5 \times 0.5}{0.05^2}$$

$$= 384.n \text{ was calculated to be } 384.$$

A total of 415 participants were recruited.

## **2.4 Data Collection Method**

Data were collected with the use of questionnaires. The Questionnaires were interviewer administered. The interviewers were volunteer Doctors, Nurses and Laboratory Scientists. The interviewers were previously briefed on the nature and significance of the study and they were trained on how to administer the questionnaire under supervision. On the clinic days of each selected health facility, the researchers met the participants, re-explained the purpose of the study and assured them of confidentiality of privileged information and a feedback after the study as told to them in the last meeting.

## **2.5 Instrument for Data Collection**

Interviewer administered questionnaire was constructed to gather the required data for the study. The Questionnaires were pre-tested at Paediatric Clinic State Hospital Sokenu in Abeokuta South Local government area and necessary corrections were made.

The questionnaire was divided into units.

Section A contains questions on Demographic data,

Section B contains questions on crisis prevention practices and treatment when it occurs,

Section C contains questions on assessing hospital related factors and the care of the children,

Section D contains questions on the frequency of clinical burden on the parents, and socio-cultural practices.

## **2.6 Ethical Consideration**

Consent to conduct the study was obtained from the ethical committee of the Olabisi Onabanjo University Teaching Hospital, Sagamu. Approval was also obtained from the from the selected health facilities for the study, discussed with the Officers in-charge on the aims and objectives of the study, the procedure and feedback was assured which could contribute to the management of their patients. At the end of each meeting with the hospital management, verbal consent was obtained.

The participants were met on the day of clinics by the researchers and the purpose, general content and nature of the study were explained and they were given assurance of confidentiality of information offered and assurance of feedback at the end of the study, and their verbal consent obtained with ease and hence, they volunteered themselves for the study.

## **2.7 Data Analysis**

Statistical analyses were conducted using SPSS for Windows version 20.0 First, descriptive statistics were generated for each survey measure. Quantitative Data collected was checked for errors, cleaned and entered. Data was summarized with proportions and means and presented using frequency tables. Frequency of Crisis was categorized as either Once or less monthly (low frequency) and twice or more monthly as High frequency of Crisis. Bivariate analyses using the  $X^2$  test were used to compare the socio-demographics of participants with the Frequency of sickle cell crisis status of their child. The level of statistical significance was set at 5%. A logistic regression model was produced with low and high frequency of crisis as outcome variable. All explanatory variables that were associated with the outcome variable in bivariate analyses, variables with a P-value of  $\leq 0.05$  were included in the logistic models.

## **3. RESULTS**

### **3.1 Socio-demographic Characteristics of Respondents**

A total of 415 patients were recruited into the study. Only 14.5% of the respondents were 40years and above, 78.5% were young adults between age 25-39yrs and 7% were youths between 20 and 24 years. Majority, 80.7% of the respondents were married and 3.9% were single parents. A significant number 8.7% of participants were divorced and 1.9% separated due to the impact of caring for children with SCD on their families with 4.8% were widowed. One quarter, 25.1% live in a polygamous family setting, 74.9% live in a monogamous family. Only 16.6% had tertiary education, 60.7% had secondary education, 20.7% with primary education and 1.9% have never been to school. About half 53.3% earn less than #18,000 monthly income. This is as shown in Table 1.

**Table 1. Frequency of socio-demographic data of participants**

<b>Variables</b>	<b>Frequency (n = 415)</b>	<b>Percentage (%)</b>
<b>Location</b>		
State Hospital Abeokuta (Aglow SC Club)	145	34.9
Egba Medical Centre Abeokuta (Hope Alive SC Club)	270	65.1
Total	415	100.0
<b>Age</b>		
20-24years	29	7.0
25-29years	96	23.1
30-34years	141	34.0
35-39years	89	21.4
40years & above	60	14.5
Total	415	100.0
<b>Marital status</b>		
Single	16	3.9
Married	335	80.7
Divorced	36	8.7
Widowed	20	4.8
Separated	8	1.9
Total	415	100.0
<b>Family structure</b>		
Monogamy	293	70.6
Polygamy	104	25.1
Single Parent	18	4.3
Total	415	100.0
<b>Divorce</b>		
Yes	36	8.7
No	352	84.8
Separated	27	6.5
Total	415	100.0
<b>Number of children with SCD</b>		
One	337	81.2
Two	62	14.9
Three	13	3.1
Four	2	0.5
Five &above	1	0.2
Total	415	100.0
<b>Level of education</b>		
Tertiary	69	16.6
Secondary	252	60.7
Primary	86	20.7
Never been to school	8	1.9
Total	415	100.0
<b>Family income month</b>		
<N18,000	221	53.3
N18,000-50,000	150	36.1
N50,000-100,000	24	4.8
N100,000-200,000	7	1.7
N200,000-300,000	4	1.0
N300,000 &above	1	0.2
Total	407	98.1
Non Respondents	8	1.9
Total	415	100.0

### 3.2 Knowledge, Attitude and Experience of Respondents about Sickle Cell Crisis

Only 39.0% had adequate knowledge of SCD, 75.2% on prevention of crisis and 62.0% on predisposing factors to sickle cell crisis. About two-third [68.0%] of participants' source of information is by hospital staffs. Majority 74.7% feel guilty and responsible for the child's illness, 15.7% were tired of caring for SCD child, and 8.7% wished the child should just die. Very few of the participants 2.4% believes it's a spiritual attack, 20% still believe there is traditional treatment that can cure the disease, 15.7% have tried traditional methods of treatment, 11.8% have used concoctions, 1.2% did rituals, 2.7% used traditional balms. This is as shown in Table 2.

**Table 2. Knowledge of parents influencing sickle cell crisis**

Variables	Frequency (n = 415)	Percentage (%)
<b>Knowledge on SCD</b>		
Adequate	162	39.0
Inadequate	253	61.0
Total	415	100.0
<b>Knowledge on prevention of SC crisis</b>		
Adequate	312	75.2
Inadequate	103	24.8
Total	415	100.0
<b>Knowledge on predisposing factors</b>		
Adequate	257	62.0
Inadequate	158	38.0
Total	415	100.0
<b>Source of information</b>		
Hospital staff	282	68.0
Books	7	1.7
Internet	2	0.5
Family & friends	120	28.9
Others	4	1.0
Total	415	100.0

Table 4 shows that majority of respondents 61.7% have been caring for less than 5years and 22.9% between 6 and 10years. Majority 81.4% have only one child with SCD and have not lost the child, 14.9% of the participants have lost one child due to SCD, 2.4% have lost two children, 1% have lost three children while only 0.2% have lost four or more children.

### 3.3 Factors Associated with Frequency of Crisis

The frequency of sickle cell crisis was statistically significantly associated with the

Marital status of the parents [ $X^2 = 24.029$  and  $p = 0.0001$ ], the family income [ $X^2 = 9.752$ ,  $p=0.0083$ ], parents level of education [ $X^2 = 18.538$ ,  $p = 0.0001$ ], the higher the level of education of parents the lower the frequency of crisis of the child; and the source of Parents information about SCD  $x^2 = 18.194$  and  $P = 0.001$ . The more professional the source of information on SCD, the lower the frequency of crisis. There was however no statistically significant relationship between the number of children with SCD [ $x^2 = 7.086$ ,  $P = 0.131$ ], the age of Parents [ $X^2 = 7.086$ ,  $P = 0.131$ ], and the frequency of crisis as shown in Table 5.

**Table 3. The duration of care and the psychological effects on the parents**

Variables	Frequency (n = 415)	Percentage (%)
<b>How long the child was diagnosed with SCD</b>		
<1 year	48	11.6
1-5 years	256	61.7
6-10 years	95	22.9
11-15 years	10	2.4
16-20 years	5	1.2
>20 years	1	0.2
Total	415	100.0
<b>Tired of caring for the child</b>		
Yes	65	15.7
No	350	84.3
Total	415	100.0
<b>Feeling of guilt as being responsible for child's illness</b>		
Yes	310	74.7
No	105	25.3
Total	415	100.0
<b>Wished the child should just die</b>		
Yes	36	8.7
No	379	91.3
Total	415	100.0

In the multiple logistic regression model, three variables were found to be independently associated with frequency of crisis. Predictors of low frequency of crisis were individuals who had parents with tertiary education [OR=2.37, CI=1.45-3.87], information from health workers [OR=0.58, C.I=0.43-0.79], and family income above minimum wage [OR=0.147, C.I=0.06-0.34]. This is as shown in Table 6.

## 4. DISCUSSION

The socio-demographic characteristics of the parents show similar stratification to other studies [12,13], none of the parents was a teenager, more than half had secondary education, over 50% earn less than the minimum

wage, so there is no reason to suggest that the participant involved in this study differed in socio-demographic characteristics from the population in our environment other than the SCD variable.

**Table 4. The Social belief of the parents concerning sickle cell disease**

<b>Social beliefs</b>	<b>Frequency (n = 415)</b>	<b>Percentage (%)</b>
<b>Believe it's a spiritual attack</b>		
Yes	10	2.4
No	405	97.6
Total	415	100.0
<b>Knowledge of any traditional treatment</b>		
Yes	83	20.0
No	332	80.0
Total	415	100.0
<b>Tried the use of traditional treatment</b>		
Yes	65	15.7
No	18	4.3
Non respondents	332	80.0
Total	415	100.0
<b>What type of traditional treatment</b>		
Concoctions	49	11.8
Rituals	5	1.2
Use of Balm/Ointment	11	2.7
Non respondents	350	84.3
Total	415	100.0

Most of the parents have inadequate knowledge of sickle cell disease as most still believe it's a form of bone disease that affects the child especially during the cold weather. Similar findings have been reported in other developing countries such as India and Nigeria [14,15]. Parents not having the appropriate knowledge of the causes of the disease, premarital screening, screening of newborn would affect their attitude towards preventing sickle cell crisis. The study further shows that about 68% of parents' source of information is in the hospital; and that the more professional the source of information on SCD, the lower the frequency of crisis. Giving correct and adequate information on the prevention and management of sickle cell crisis is significant in the reduction of sickle cell crisis. Similar studies have reported that caregivers knew the basics of the disease and how to manage unwanted complications at home because they were given clear information by Doctors and Nurses each time they visit the clinic [16-18].

Majority of the parents (over 80%) had only one child with sickle cell disease. This could be explained by the fact that, couples with sickle

cell trait will have each of their pregnancies having a 25% chance of giving birth to a child affected by sickle cell disease [19]. Furthermore, the marital status shows significant influence in the frequency of crisis as children living with single parents, widows & divorced parents have lower frequency of crisis than children living with both parents. Probably single parents pay more attention and dedication to their care of their children as it is sole responsibility of a single person and not the family again. Majority also have their marriage intact while some divorced their spouse because of the burden of care the children requires. If this is done to prevent giving birth to more SCD child, it's a welcome development as it will reduce the prevalence of the disease in the community. Counselling sessions by psychologists and social workers should be arranged for parents and children with SCD. Government should ensure that hospitals at the 3 tiers of government operate special clinics for sickle cell patients. Massive awareness campaigns at the registry, religious organisations for citizens about the importance of making inquiry about the sickle cell status of future spouse. Health education programmes should start from schools, so we can improve the knowledge about this disease in present students. As they are the future parents, this knowledge will alter their attitude and behaviour regarding this disease and this will help in reducing child births with sickle cell disease.

The level of parent education was another variable that shows significant influence in the frequency of crisis. Significant proportion of children of parents with tertiary educational status have low frequency of crisis compared to others. This is similar to what has been reported in several other studies [19,20]. An educated parent has more access to information on the disease more than uneducated parents. Practice of preventive methods, living in a hygienic environment, screening of newborn, pre-marital screening are practices that are easily understood and carried out by educated parents than the illiterate and poor parents. Health practitioners and policy makers should pay attention to prevention measures by setting up sickle cell screening and genetic counselling programmes in high prevalence regions. Mass screening programmes provide an ideal opportunity to make people aware. Sickle cell associations or clubs in each local government should be aided by the government and health professionals so as to increase the level of information, education, rehabilitation and

financial support. Parents and the affected can discuss freely and be counselled, as this will serve as psychosocial support for both. Welfare systems should be made available to the parents or care giver and sickle cell patients. Government should ensure the health insurance scheme get to every citizen and not just civil servants and corporate employees.

The study also reveals that significant portion of the parents of children who earn below minimum wage of #18,000 naira monthly have crisis more frequently. Low income makes it difficult to practice prevention of sickle cell crisis as they are unable to meet the daily requirements of buying nutritious foods, drugs, providing warmth and accessing health care services for their children. Studies [21,22] have concluded that the

cost of daily maintenance of SC patients is huge in terms of drugs, nutrition, hospitalization, prevention of crisis and that the affected individual in the family suffers a burden of anxiety, frequent illness, excessive mortality rates, ignorance and lack of appropriate health services. This also agree with other studies [22,23] which concluded that people who are illiterate and poor are subjected to economic exploitation, deprivation and social isolation which are reflected in their low quality of life. This implies that those who are poor and have low family income are unable to implement preventive measures even if they have adequate knowledge in prevention of sickle cell crisis. This therefore entails that for parents and caretakers to be able to practice preventive measures they should have enough resources.

**Table 5. Factors associated with the frequency of sickle cell crisis**

	Frequency of crisis in a month		Total
	Low	High	
<b>Marital status</b>			
Single	13(8.9%)	3(1.1%)	16(3.9%)
Married	104(71.2%)	231(85.9%)	335(80.7%)
Divorced	14(9.6%)	22(8.2%)	36(8.7%)
Widowed	9(6.2%)	11(4.1%)	20(4.8%)
Separated	6(4.1%)	2(0.7%)	8(1.9%)
Total	146(100.0%)	191(100.0%)	415(100.0%)
<b>Age</b>			
20-24 years	9(6.2%)	20(7.4%)	29(7.0%)
25-29 years	30(20.5%)	66(24.5%)	96(23.1%)
30-34 years	49(33.6%)	92(34.2%)	141(34.0%)
35-39 years	29(19.9%)	60(22.3%)	89(21.4%)
40 years & above	29(19.9%)	31(11.5%)	60(14.5%)
Total	146(100.0%)	269(100.0%)	415(100.0%)
<b>Number of children with SCD</b>			
One	124(84.9%)	213(79.2%)	337(81.2%)
Two	17(11.6%)	45(16.7%)	62(14.9%)
Three	3(2.1%)	10(3.7%)	13(3.1%)
Four	2(100.0%)	0(0.0%)	2(0.5%)
Five	0(0%)	1(0.4%)	1(0.2%)
Total	146(100.0%)	269(100.0%)	415(100.0%)
<b>Parents level of education</b>			
Tertiary	36(24.7%)	33(12.3%)	69(16.6%)
Secondary	69(47.3%)	183(68.0%)	252(60.7%)
Primary	38(26.0%)	48(17.8%)	86(20.7%)
Never been to schl	3(2.1%)	5(1.9%)	8(1.9%)
Total	146(100.0%)	269(100.0%)	415(100.0%)
<b>Family income/month</b>			
<N18,000	113(77.3%)	127 (47.3%)	240(57.8%)
>N18,000-50,000	33(22.7%)	142(52.7%)	175(43.2%)
Total	146(100.0%)	269(100.0%)	415(100.0%)
<b>Source of information</b>			
Hospital staff	108(74.0%)	174(64.7%)	282(68.0%)
Books	1(0.7%)	6(2.2%)	7(1.7%)
Internet	2(1.4%)	0(0.0%)	2(0.5%)
Family & friends	31(21.2%)	89(33.1%)	120(28.90%)
Others	4(2.7%)	0(0.0%)	4(1.0%)
Total	146(100.0%)	269(100.0%)	415(100.0%)



**Table 6. Multivariate logistic regression**

	Odds ratio [C.I]
<b>Level of education of parent</b>	
Nil education	1.00
Educated	2.37 [1.45-3.87]
<b>Marital status of parent</b>	
Married	0.82 [0.56-1.20]
Not married	1.00
<b>Source of information</b>	
Health workers	0.58 [0.43-0.79]
Others	1.00
<b>Family income</b>	
>#18,000	0.147 [0.064-0.335]
< #18,000 (minimum wage)	1.00

**5. CONCLUSION**

The level of care and support given to SCD children may reflect in their parents' level of education, depth of knowledge about the disease and financial capability. Attention to the psychosocial problems of parents and/or caregivers of these children is of utmost importance. The financial burden the disease place on the parents makes the care of these children difficult and unbearable thereby worsening the quality of life of SCD patients.

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**COMPETING INTERESTS**

Authors have declared that no competing interests exist.

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