

## Original Research Article

### KNOWLEDGE OF SICKLE CELL DISEASE AMONG UNIVERSITY STUDENTS IN PORT HARCOURT

#### ABSTRACT

**Background:** Sickle Cell Disease (SCD) is a hereditary haemoglobinopathy that has been related with significant mortality in sub-Saharan Africa and Nigeria. Knowledge on cause, prevention and risk factors are important for adequate control of the occurrence of SCD in Nigeria.

**Method:** A cross sectional study on the awareness of SCD was carried out among undergraduate students in Port Harcourt, Nigeria. A structured questionnaire was interviewer-administered to 146 students.

**Results:** The results of the study showed that 97.9% claim to have heard about sickle cell, while 68.5% indicated that the source of information on sickle cell was in school. One hundred and twenty-seven (87%) indicated that SCD describes abnormal blood cells. A summary of the level of awareness of SCD among the students showed that only 61 (42%) of the respondents had a good awareness on SCD. There were significant relationships of poor awareness of SCD among male students, students between 16 -20 years old and students with an average family income of at least N150,000.

**Conclusion:** The findings of the study buttress the need for improved awareness on SCD especially for the family and increased awareness campaigns on every available media platform.

**Keywords:** *Knowledge, awareness, sickle cell disease, undergraduates, Port Harcourt*

#### INTRODUCTION

Sickle cell disease (SCD) is a serious disorder of the blood that has a wide array of deleterious effects on the human body and psyche it is caused by pathological haemoglobin mutation which is common worldwide [1]. This mutation is a structural variant of normal adult haemoglobin (HbA), which is inherited as a Mendelian trait [2–4]. Carriers, or heterozygotes (AS individuals), inherit an HbS allele from one parent and an HbA allele from the other [5]. These individuals are usually asymptomatic. Homozygotes [SS individuals] who have inherited HbS alleles from both parents suffer from sickle cell anaemia, which often leads to acute and chronic complications [6]. SCD is one of the most common hereditary diseases occurring worldwide, which may affect any organ or system of human body. It is an irreversible, manageable health problem predominantly seen amongst various tribes, worldwide [7]. Persons with the disease are subject to a high burden of acute and chronic pain, greater susceptibility to infections, strokes, neurocognitive deficits, progressive organ and tissue deterioration, and a generally low health-related quality of life [8]. Without treatment, which is rarely available in low-income high-burden countries, it is assumed that most children born with the disease die in their first years of life. Worldwide, SCD contributes a significant burden that is not amply addressed [9]. It is estimated that 312,000 children will be born worldwide with SCD annually With the greatest burden existing in Sub-Saharan Africa, where 75% of the world sickle cell disease occurs [10]. Nearly 90 percent of the world's SCD population lives in three countries: Nigeria, India, and the Democratic Republic of Congo, where the disease affects up to 2 percent of the population, and the

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carrier prevalence rate [sickle cell trait] is as high as 10 to 30 percent [11,12]. Nigeria alone has been estimated to have at least 150,000 newborns born with SCD annually. Estimates are challenging because of the lack of federal newborn screening programs; however, approximately 700,000 births occur per year and the prevalence of SCD in newborns was 3 percent in a regional newborn screening program [7,13]. The problem of the persons living with SCD goes beyond the debilitating health consequences of the illness. People are frequently stigmatized and discriminated against; this also causes families to hide their children whenever they are sick [14]. This study aimed to evaluate the prevalence, perceptions, understanding and awareness of sickle cell disease in university students in Port Harcourt, Nigeria Uganda. This knowledge is critical in drawing attention to possible areas for intervention and change to facilitate better outcomes in the prevention, recognition and management of sickle cells.

**Comment [U3]:** Nice epidemiological flow but it will be nice to also cite other epidemiological study carried out in the region where the study is carried out such as the study by AKABA in Calabar which is close

**Comment [U4]:** Please I don't understand Nigeria in Uganda

## **METHODS**

### **Study Area**

The study was carried out in the Rivers State University, Port Harcourt. The University is located in the Diobu area of Port Harcourt, Rivers State, Nigeria. The university consists of 9 academic faculties and 61 departments. The university hosts students from various socio-cultural backgrounds in Nigeria and serves as a catchment area for tertiary education in southern Nigeria.

### **Study Design**

The descriptive cross-sectional study design was adopted for the study.

### **Ethical consideration**

Ethical approval for the study was obtained from the Research and Ethics committee of the Rivers State University prior to commencement of the study. Willing informed consent was also obtained from all willing participants in the study and no personal identifiers of the respondents were collected for the purpose of the study.

### **Study Sample**

The target population for the study included One hundred and forty-six (146) undergraduate students of the Rivers State University who were purposively selected for the study.

### **Data Collection**

A structured interviewer-administered questionnaire was used to collect socio-demographic data, data on knowledge of SCD, Awareness of genotype testing and Personal and family history of SCD from the respondents.

### **Data Analysis**

The data was analysed with the statistical package for social sciences (SPSS) version 25. All results were presented in mean, frequency and percentage as appropriate. Chi-square was used to assess the association of socio-demographic data and level of knowledge of sickle cell anaemia among the respondents. All analysis was done at a 95% confidence interval and a p-value less than 0.05 was considered significant.

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## RESULTS

**Table 1 socio-demographic profile**

<b>Variable</b>	<b>Frequency (n = 146)</b>	<b>Percent</b>
<b>Age</b>		
16 – 20 years	132	90.4
21 – 25 years	14	9.6
Mean ± standard deviation	18.46 ± 1.909	
<b>Sex</b>		
Male	51	34.9
Female	95	65.1
<b>Faculty</b>		
Engineering	38	26.0
Humanities	36	24.0
Law	47	32.2
Sciences	25	17.1
<b>Level of study</b>		
100	128	87.7
200	11	7.5
300	3	2.1
400	4	2.7
<b>Marital status</b>		
Single	144	98.6
Married	2	1.4
<b>Religion</b>		
Christianity	146	100.0
<b>Average family income (₦)</b>		
< 50 ,000	14	9.6
50,000 – 100,000	17	11.6
100,001 – 150,000	30	20.5
150,001 – 200,000	49	33.6
>200,000	36	24.7

The demographic profile showed that most of the respondents (90.4%) were between 16 – 20 years old and the mean age was 18.46 ± 1.90 years. Most of the respondents were female (65.1%). Majority (98.6%) of the respondents were single while 1.4% were married as shown in Table 1.

**Table 2 Awareness of sickle cell**

<b>Variable</b>	<b>Frequency (n = 146)</b>	<b>Percent</b>
<b>Have you heard about sickle cell disease?</b>		
Yes	143	97.9
No	3	2.1
<b>Source of information</b>		
Internet	30	20.5
Radio/TV	27	18.5
School	100	68.5
Health facility/workers	21	14.4
Family	23	15.8
Awareness campaign	1	0.7
<b>Sickle cell disease describes</b>		
An infection	4	2.7
A problem with the brain	13	8.9
Abnormal bold cells	127	87
A sexually transmitted disease	1	0.7
I don't know	1	0.7
<b>How people get sickle cell disease</b>		
They get them from their parents	129	88.4
They are contagious and gotten from other people	3	2.1
They are gotten as a result of old age	5	3.4
They get them from a blood transfusion	1	0.7
I don't know	8	5.5
<b>Do you know what they call sickle cell carrier?</b>		
Yes	130	89
No	16	11
<b>If yes, who is a carrier?</b>		
Someone who has one sickle cell gene and can transfer it to their children	64	49.2
Someone who has two sickle cell genes and can transfer it to their children	45	34.6
Someone who is carrying a sickle cell infection	10	7.7
Someone who has sickle cell in their family	7	5.4
I don't know	4	3.1
<b>How can you check if someone has sickle cell</b>		
By doing an infection test	19	13
By doing a blood test for abnormal cells	116	79.5
Doing a brain test for abnormal brain cells	4	2.7
I don't know	7	4.8
<b>Have you heard of genotype testing?</b>		
Yes	141	96.6
No	5	3.4

Table 2 shows the respondent's awareness of sickle cell disease. Most of the respondents (97.9%) claim to have heard about sickle cell, while 68.5% indicated that the source of

information on sickle cell was in school. One hundred and twenty-seven (87%) indicated that SCD describes abnormal blood cells, while 88.4% of that SCD is gotten from a person's parent.

**Table 3 Awareness of the complications of sickle cell anaemia**

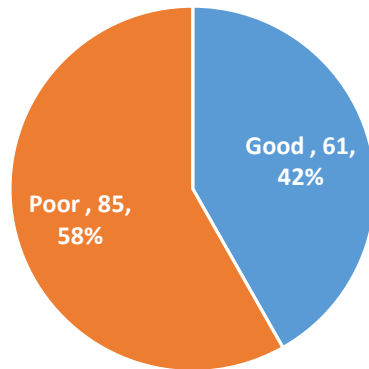
Variable	Frequency (percent)		
	Yes	No	I don't know
<b>Correct perceptions of the complications of SCD</b>			
Frequent chest infections	45 (30.8)	27 (18.5)	74 (50.7)
Recurrent bone pain	79 (54.1)	17 (11.6)	50 (34.2)
Poor school performance	28 (19.2)	69 (47.3)	49 (33.6)
Leg ulcers	19 (13.0)	47 (32.2)	80 (54.8)
Problems in pregnancy	42 (28.8)	45 (30.8)	59 (40.4)
Recurrent hospital admissions	112 (76.7)	8 (5.5)	26 (17.8)
Problems in pregnancy	31 (21.2)	50 (34.2)	65 (44.5)
Recurrent fever, jaundice, and poor growth	101 (69.2)	9 (6.2)	36 (24.7)
<b>Incorrect perceptions about complications of SCD</b>			
Brain cancer	11 (7.5)	53 (36.3)	82 (56.2)
Poor IQ	17 (11.6)	70 (47.9)	59 (40.4)
Cannot conceive	8 (5.5)	105 (71.9)	33 (22.6)
Short term memory	20 (13.7)	41 (28.1)	85 (58.2)

Table 3 shows the pattern of correct and incorrect responses on the awareness of SCD complications among the respondents.

**Table 4 Awareness of genotype testing**

<b>Variable</b>	<b>Frequency (n = 146)</b>	<b>Percent</b>
<b>Have you done a genotype test before?</b>		
Yes	121	82.9
No	23	15.8
I don't know	2	1.4
<b>If yes, what was the reason for the test</b>		
Routine test	8	6.6
At school entry	70	57.9
At physician's request	4	4.1
For medical fitness	35	28.9
Cannot remember reason	3	2.5
<b>Can you remember your genotype</b>		
Yes	127	91.4
No	12	8.6
<b>What is your genotype</b>		
AA	104	74.8
AS	23	16.5
SS	2	1.4
SC	0	0.0
I'm not sure	10	7.2
<b>Do you know the genotype of your parents?</b>		
Yes	142	97.2
No	4	2.8
<b>Do you think it is necessary to know your genotype</b>		
Yes	137	93.8
No	4	2.7
Not sure	5	3.4
<b>When both father and mother are AS, what is the likelihood that they will have a baby with sickle cell</b>		
Every time she gets pregnant	3	2.1
Half of the time she gets pregnant	19	13.0
If she has 4 children, one of them will have sickle cell	86	58.9
Each time she gets pregnant it may be a baby with sickle cell anemia, one in four chances	27	18.5
I don't know.	11	7.5

Table 4 shows the respondent's awareness on genotype testing. Many of the respondents (82.9%) had done a genotype test before. The most common reason for the genotype test was during initial medical examination for school entry (57.9%) and the least common reason was at the physician's request (4.1%). The most common genotype was reported to be AA (74.8%) and the least common genotype was SS (1.4%) and none reported to be SC genotype. Most of the respondents (97.2%) reportedly knew their parent's genotype while 93.8% think it is necessary to know their genotypes.



**Figure 1: Overall rating for awareness of SCD**

Figure 1 shows that 61 (42%) of the respondents had a good awareness on SCD.

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**Table 5 Relationship between socio-demographic data and level of knowledge of sickle cell anemia**

<b>Variable</b>	<b>Frequency (n = 146)</b>	<b>Percent</b>
<b>Awareness of SCD</b>		
<b>Age</b>	<b>Good</b>	<b>Poor</b>
16 – 20 years	59 (40.4)	73 (50.0)
21 – 25 years	2 (1.4)	12 (8.2)
<b>Chi-square</b>	<b>4.813</b>	
<b>P value</b>	<b>0.028*</b>	
<b>Sex</b>		
Male	13 (8.9)	38 (26.0)
Female	48 (32.9)	47 (32.2)
<b>Chi-square</b>	<b>8.551</b>	
<b>P value</b>	<b>0.003*</b>	
<b>Faculty</b>		
Engineering	19 (13.0)	19 (13.0)
Humanities	12 (8.2)	24 (16.4)
Law	21 (14.4)	26 (17.8)
Sciences	9 (6.2)	16 (11.0)
<b>Chi-square</b>	<b>2.617</b>	
<b>P value</b>	<b>0.454</b>	
<b>Marital status</b>		
Single	61 (41.8)	83 (56.8)
Married	0 (0.0)	2 (1.4)
<b>Chi-square</b>	<b>1.455</b>	
<b>P value</b>	<b>0.228</b>	
<b>Level of study</b>		
100	52 (32.6)	76 (52.1)
200	4 (2.7)	7 (4.8)
300	2 (1.4)	1 (0.7)
400	3 (2.1)	1 (0.7)
<b>Chi square</b>	<b>2.781</b>	
<b>P value</b>	<b>0.427</b>	
<b>Average family income</b>		
< 50,000	3 (2.1)	11 (7.5)
50,000 – 100,000	7 (4.8)	10 (6.8)
100,000 – 150,000	19 (13.0)	11 (7.5)
150,000 – 200,000	22 (15.1)	27 (18.5)
>200,000	10 (6.8)	26 (17.8)
<b>Chi square</b>	<b>11.213</b>	
<b>P value</b>	<b>0.024*</b>	

\*Statistically significant ( $p < 0.05$ )

Table 5 shows that there was a significant relationship between of sickle cell disease and the sex of the respondents, p value – 0.003. Other socio-demographic factors shared no significant relationships. The results showed that 50% of the respondents aged 16 – 20 years had poor awareness of SCD, while most of the male respondents were found to have poor awareness of SCD. The study also showed that majority of the respondents with an average family income of at least 150,000 had poor awareness of SCD.

## DISCUSSION

The study showed a high proportion of the students have heard about SCD as only 2% of the students have not heard about SCD before. This is consistent with findings of similar studies in Nigeria which reported at least 88% of students in universities have heard about SCD [7,15,16]. The relatively high proportion of students that have heard about SCD was reported in other studies across Africa also [1,13,17]. The relatively high proportion of students that have heard about SCD may be attributed to the recent upsurge in the use of the internet for information dissemination across Africa [12]. The study also showed that the school was the most common source of information on SCD [68.5%], followed by the internet [20.5%] and Radio/TV [18.5%]. This is however in contrast with the finding of Orish [18] which reported that most common source of information on SCD for undergraduates in Ghana were Radio/TV [70%] and the internet [50%]. Similarly, a study by Kadima [9] reported that the TV and internet account for more than 50% of the source of knowledge of SCD among the students in the Democratic Republic of Congo [DRC]. This disparity in the source of knowledge on SCD with other studies in Africa could indicate that there is little information on SCD accessible via the TV/radio or the internet in Nigeria as most of the information on SCD is available at academic institutions or health centres [15].

A few of the respondents [11.6%] indicated that SCD is an infection or a problem with the brain. Majority [88.4%] of the respondents reported that SCD is gotten from an individual's parents. About 38% of the respondents indicated that brain cancer, poor IQ, infertility and short-term memory are complications of SCD. Consequently, a classification of the overall awareness of SCD among the students indicate that 58% of the students had poor awareness of SCD. This is consistent with the findings of a previous studies which reported that more than 50% of undergraduates were found to have poor awareness of SCD [1,13]. Although many student know or have hear about SCD in one form or the other, there seem to be a generally poor knowledge on the causes, complications and associated risk factors among many students [1,3,19,20].

The current study showed that only 82.9% of the respondents had done their genotype testing before, with school entry being the most common reason for genotype testing [57.9%]. This is in contrast with the findings of Tusubira [13] which reported that 80% of the students interviewed have had a genotype test done, especially during school entry in Uganda. Similarly, Uche [15] reported that 78% of the undergraduates in Lagos had undergone

genotype testing especially during school entry process. The contrast in the proportion of students that have done genotype testing may be attributable to a lack of awareness of testing done during medical examinations when they were registering. A breakdown in genotype testing equipment during the registration process have also been reported to occur, hence some students may not eventually have a genotype test [10,12,13,15].

Most [50%] of the respondents aged 16 – 20 years had poor awareness of SCD, while most of the male respondents [26.0%] were found to have poor awareness of SCD. The association of gender and awareness of SCD have been reported to be significantly poorer among male students in other studies also [1,3,16,18,21]. Many males have been reported to have little concern about SCD as long as they are not affected by it directly or indirectly [7,15]. The current study also showed that majority of the respondents with an average family income of at least ₦150,000 had poor awareness of SCD. This is in contrast with the reports of Uche [15] which reported that majority of students from families with an average income above ₦150,000 per year seem to have good awareness of SCD compared to students from families with lesser income. The disparity in the proportion of awareness among the students based on their socio-economic status could be attributed to either lack of interest and sometimes lack of adequate sources of information among the different socio-economic classes [17,21,22].

## **CONCLUSION**

The findings of the study showed that there was some form of awareness of SCD among the students. However, more than half of the students had a poor awareness. The most common source of knowledge was found to be the school which is not enough to increase the awareness of SCD in the current digital age. Poor awareness of SCD was mostly significant among younger students aged 16 – 20 years while the level of study was not significantly associated with poor awareness among the students. The findings of the study buttress the need for improved awareness on SCD especially for the family and increased awareness campaigns on every available media platform.

## **REFERENCES**

1. Haywood C, Lanzkron S, Bediako S, Strouse JJ, Haythornthwaite J, Carroll CP, et al. Perceived Discrimination, Patient Trust, and Adherence to Medical Recommendations Among Persons with Sickle Cell Disease. *J Gen Intern Med.* 2014;29(12):1657–62.
2. Daak AA, Elsamani E, Ali EH, Mohamed FA, Abdel-Rahman ME, Elderderly AY, et al. Sickle cell disease in western Sudan: genetic epidemiology and predictors of

- knowledge attitude and practices. *Trop Med Int Heal* [Internet]. 2016 May 1 [cited 2020 Mar 21];21(5):642–53. Available from: <http://doi.wiley.com/10.1111/tmi.12689>
3. Bediako SM, Lanzkron S, Diener-West M, Onojobi G, Beach MC, Haywood C. The Measure of Sickle Cell Stigma: Initial findings from the Improving Patient Outcomes through Respect and Trust study. *J Health Psychol*. 2016;21(5):808–20.
  4. Alotaibi MM. Sickle cell disease in Saudi Arabia: A challenge or not. *J Epidemiol Glob Health* [Internet]. 2017 Jun 1 [cited 2020 Mar 21];7(2):99. Available from: <https://www.atlantispress.com/article/125905808>
  5. Zempsky WT, Loiselle KA, McKay K, Lee BH, Hagstrom JN, Schechter NL. Do children with sickle cell disease receive disparate care for pain in the emergency department? *J Emerg Med*. 2010 Nov;39(5):691–5.
  6. Piel FB, Patil AP, Howes RE, Nyangiri OA, Gething PW, Dewi M, et al. Global epidemiology of Sickle haemoglobin in neonates: A contemporary geostatistical model-based map and population estimates. *Lancet*. 2013 Jan;381(9861):142–51.
  7. Olakunle OS, Kenneth E, Olakekan AW, Adenike OB. Knowledge and attitude of secondary school students in Jos, Nigeria on sickle cell disease. *Pan Afr Med J*. 2013;15:1–9.
  8. Ugwu NI. Sickle cell disease: Awareness, knowledge and attitude among undergraduate students of a Nigerian tertiary educational institution. *Asian J Med Sci*. 2016;7(5):87–92.
  9. Kadima BT, Gini Ehungu JL, Ngiyulu RM, Ekulu PM, Aloni MN. High rate of sickle cell anaemia in Sub-Saharan Africa underlines the need to screen all children with severe anaemia for the disease. *Acta Paediatr Int J Paediatr*. 2015 Dec 1;104(12):1269–73.
  10. Abhulimhen-Iyoha B, Israel-Aina Y, Joel-Utomakili K. Sickle cell anaemia: Morbidity profile and outcome in a paediatric emergency setting in Nigeria. *African J Med Heal Sci*. 2015;14(2):79.
  11. GO E, NB O, ML O, KI A. Sickle Cell Disease in Nigeria -----A Review. *IOSR J Dent Med Sci*. 2017;16(01):87–94.
  12. Piel FB, Hay SI, Gupta S, Weatherall DJ, Williams TN. Global Burden of Sickle Cell Anaemia in Children under Five, 2010–2050: Modelling Based on Demographics, Excess Mortality, and Interventions. *PLoS Med*. 2013 Jul;10(7):e1001484.
  13. Tusuubira SK, Nakayinga R, Mwambi B, Odda J, Kiconco S, Komuhangi A. Knowledge, perception and practices towards sickle cell disease: A community survey among adults in Lubaga division, Kampala Uganda. *BMC Public Health* [Internet]. 2018 Apr 27 [cited 2020 Mar 21];18(1):561. Available from: <https://bmcpublihealth.biomedcentral.com/articles/10.1186/s12889-018-5496-4>
  14. Kadima BT, Gini Ehungu JL, Ngiyulu RM, Ekulu PM, Aloni MN. High rate of sickle cell anaemia in Sub-Saharan Africa underlines the need to screen all children with severe anaemia for the disease. *Acta Paediatr* [Internet]. 2015 Dec 1 [cited 2020 Mar 21];104(12):1269–73. Available from: <http://doi.wiley.com/10.1111/apa.13040>
  15. Uche E, Olowoselu O, Augustine B, Ismail A, Akinbami A, Dosunmu A, et al. An assessment of knowledge, awareness, and attitude of undergraduates toward sickle cell

- disease in Lagos, Nigeria. *Niger Med J*. 2017;58(6):167.
16. Adeyemo TA, Ojewunmi OO, Diaku-Akinwumi IN, Ayinde OC, Akanmu AS. Health related quality of life and perception of stigmatisation in adolescents living with sickle cell disease in Nigeria: A cross sectional study. *Pediatr Blood Cancer*. 2015 Jul 1;62(7):1245–51.
  17. G Ndeezi CKAHDMTHISJNSKCNRWRJ. Aceng burden of sickle cell trait and disease in the Uganda sickle surveillance study (US3): a cross-sectional study *lancet glob. Health (Irvine Calif)*. 2016;4:e195–200.
  18. Orish V, Onyebor O, Sanyaolu A, Iriemenam N. Evaluating the knowledge of sickle cell disease and hemoglobin electrophoretic pattern among people living in Sekondi-Takoradi Metropolis, Ghana. *J Med Trop [Internet]*. 2014 [cited 2020 Mar 21];16(2):56. Available from: <http://www.jmedtropics.org/text.asp?2014/16/2/56/139047>
  19. Sickle-cell disease: a strategy for the WHO African region. Report AFR/RC60/8. World Health Organization; 2010.
  20. Nalbandian RM, Nichols BM, Camp FR, Lusher JM, Conte NF, Henry RL, et al. Dithionite tube test--a rapid, inexpensive technique for the detection of hemoglobin S and non-S sickling hemoglobin. *Clin Chem [Internet]*. 1971 Oct [cited 2020 Mar 21];17(10):1028–32. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/5095141>
  21. Orish V, Onyebor O, Sanyaolu A, Iriemenam N. Evaluating the knowledge of sickle cell disease and hemoglobin electrophoretic pattern among people living in Sekondi-Takoradi Metropolis, Ghana. *J Med Trop*. 2014;16(2):56.
  22. Serjeant GR, Serjeant BE, Mason KP, Gibson F, Gardner R, Warren L, et al. Voluntary premarital screening to prevent sickle cell disease in Jamaica: does it work? *J Community Genet [Internet]*. 2017 Apr 1 [cited 2020 Mar 21];8(2):133–9. Available from: <http://link.springer.com/10.1007/s12687-017-0294-8>