

## **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

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.

## **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 host 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 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<br/>(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  $18.46 \pm 1.90$  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<br/>(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**

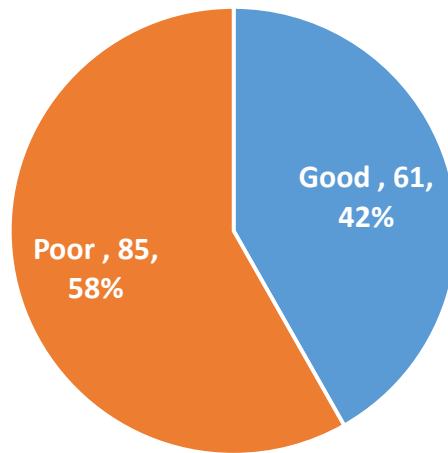
| Variable  | Frequency (percent) |            |              |
|---|---------------------|------------|--------------|
|   | Yes                 | No         | I don't know |
| <b>Correct perceptions of the complications of SCD</b>  |                     |            |              |
| Frequent chest 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<br/>(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<br/>(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,                | 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.

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