



## Prevalence and burden of Sickle Cell Disease among Undergraduates of Obafemi Awolowo University, Ile-Ife

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### Key words:

Prevalence,  
Burden,  
Sickle Cell  
Disease (SCD),  
Obafemi  
Awolowo  
University,  
Undergraduates

### ABSTRACT

**Background:** Sickle cell disease (SCD) is the most common form of haemoglobinopathy in Nigeria but there is paucity of data for its effects on undergraduate students in universities despite the fact that this population of people suffer more burdens of the disease due to relative lack of parental care and their recently increased educational demand.

**Objective:** This study examined the prevalence of SCD among undergraduates in Obafemi Awolowo University' Health Centre over a 5 year period. It also explored the burdens (educational, psychological, socio-cultural and financial) of SCD on students with sickle cell disorder as well as the relationship among the variables pain severity, monthly income, the psychological and socio-cultural burden of SCD).

**Methods:** The study employed a descriptive design. First a retrospective analysis of SCD cases in the total admission for a 5 year period at the University health centre was done. Then an adapted version of the psychosocial pain assessment form was used to assess 4 areas of burden of SCD in the study population. It had two sections with 28 items. Section A of the questionnaire assessed the socio-demographic status of the participants with five items. Section B is a 23 item parts that assess the financial, psychological, educational and socio-cultural burden. 280 sample size was calculated for the study and respondents were purposively selected on the SCD clinic days at the health centre, Snow balling technique was used to identify others not attending clinic. The descriptive and inferential statistics were done using SPSS version 20.

**Results:** The findings from the study revealed that the prevalence of SCD among the total admission of OAU health centre over the five year period studied was 21.6%. For hospitalization record outside the health centre during school breaks, 24.2% of the respondents discharged against medical advice for financial reasons and 9.8% had a monthly income above N20,000. 68% had significantly severe pain in the last one year. 12.7% had at least two semesters to repeat which they claimed was due to their health challenges. 44% had significant psychological burden while 37.3% have socio-cultural burden. The relationship among the average monthly income, pain severity and reported burdens showed that all the tested variables' p-value was less than 0.05.

**Conclusion:** The study concluded that OAU undergraduates living with SCD were burdened educationally, psychologically and socio-culturally. The pain severity and monthly income of the respondents shows statistically significant effects on the studied (psychological and socio-cultural) burdens.

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## INTRODUCTION

In December 2008, the 63rd session of the United Nations (UN) General Assembly adopted a resolution on the "recognition of sickle cell anaemia as a public health problem" and urged members

states and UN organizations to raise awareness of SCD on June 19 of each year<sup>1</sup>. Despite the fact that the UN has called for global efforts "to bring the disease out of the shadows" relatively little attention has been given to assessing the burden of SCD and to reduce it in Africa, where about 85% of children

with SCD are born.<sup>2</sup>

Obafemi Awolowo University (OAU) management created the social workers unit, which stems from the increase burden of chronic diseases among the undergraduates of which SCD ranked high. Most chronic health conditions (e.g. HIV, diabetes, cancer or malaria) have organised primary health care programs that are well funded by individuals, agencies and government<sup>3</sup>. There is inadequate attention and little investment in public health SCD programs, compared to those already in place for other chronic conditions.<sup>4</sup> Such program, if available will promote widespread screening, health education and treatment to prevent or manage SCD complications.

The aim of the study therefore was to examine the prevalence of SCD among the admitted undergraduates in Obafemi Awolowo University Health Centre and the burdens (educational, psychological, socio-cultural and financial) of SCD on the affected students. The study also examined the effects of crises pain and monthly income on the psychological and socio-cultural burdens of SCD.

## **METHODS**

### **Study area.**

The study was carried out in the Obafemi Awolowo University health centre which is a primary health centre that provides comprehensive primary health care services to the University community. As of the time of data collection according to the student affairs division, the student population was put at 35,000 distributed over 82 departments, 13 faculties and 2 colleges of Obafemi Awolowo University. The health centre operates a 24-hour service and has 24 bed spaces for admitting patients.

### **Study design, study population and sample**

It is an observational non-experimental research that examined the prevalence of SCD, burden of care and disease on the patients living with SCD among undergraduate students in Obafemi Awolowo University, Ile-Ife, Osun-State, Nigeria.

There is a mandatory pre-admission genotype screening for all newly admitted undergraduates of the university who indicated in the health screening forms that they do not know their genotype.

All admission record of sick undergraduates over the 5 years period was assessed for this study, to calculate the prevalence of SCD for this period under study. 485 cases of SCD were gotten from total admission of 2,241. To determine the sample size,  $n$ , for assessing burden of SCD among current undergraduates with HbSS Cochran Formula ( $n = Z^2pq/d^2$ )<sup>5</sup> was used, where  $Z$  is the standard normal variance where confidence level is 1.96 at 95%;  $p$  is the prevalence of SCD over the 5 years period under study = 21.6%;  $q = 1-p$  and  $d$  is the absolute precision or error margin tolerated, chosen as 5%. The computed value of  $n$  was 260. To allow for attrition rate, 280 Questionnaires were given out, 265 were returned (95%) and 244 questionnaire (87%) were correctly filled and fit for data analysis. The data were collected over a period of 4 weeks.

Ethical consideration for this study was processed through the Institute of Public Health, Obafemi Awolowo University, Ile-Ife while the research committee of the health centre also gave approval to conduct this study.

### **Survey tool, measures and procedures**

Purposive, non-probability sampling was used to select subjects for this study. SCD patients attending clinic at health centre were recruited on the clinic days, others were traced to their hosts by snowballing approach till the calculated 280 sample was obtained. Written consent was obtained.

Data was collected using a structured questionnaire adapted from Psychosocial Pain Assessment form<sup>6</sup> which comprises of two sections; Section A had 5 items which assessed the socio-demographic data of the SCD patients while Section B had 23 items distributed under 4 domains. The domains include; financial, educational, psychological, socio-cultural/stigmatization factors. The level of burden were graded under 6 responses for both the

psychological and socio-cultural/stigmatization data - 'all of the time', 'most of the time', 'more than half of the time', 'less than half of the time', 'some of the time', and 'at no time'.

### Data analysis

Data generated from these questionnaires were analysed by means of descriptive statistics using frequency distribution tables. Inferential statistics by chi-square analysis and p values computation was used to explore the relationship between the reported burdens and other predictor factors. Analyses were conducted using the Statistical Package for Service Sciences (SPSS Version 20). The level of statistical significance was  $P < 0.05$ .

### RESULTS

The age of respondents ranged from 17 to 31 years, with the mean age of 22.3 and standard deviation of 3.6 years. Majority of the respondents interviewed were females (57.8%), Yoruba (87.3%) and the least tribes were Igbo and Hausa with a value of 1.6% each (Table I).

The result was a retrospective study of all admitted undergraduates over a period of five years excluding all repeated admissions in the same year. Results from the study showed that the frequency of SCD among males was low compared to that of the females. The calculated prevalence of SCD among the OAU students over the five year period was 21.6% (Table II).

In Table III, majority of the respondents (91.4%) depended largely on their parents with the average monthly income of respondents ranges between less than N5,000 and above N20,000. Most of the respondents spent less than N2,500 on the average in a month on SCD when not on admission for their routine drugs as their health Insurance coverage (TSHIP) offsets their bills compared While 2.1% of the respondents reported that they spent between N7,501 and N10,000 on SCD in a month. Considering the average spending while on admission, about 92% of respondents spent less

than N10,000 annually on admission related issues (most of them registered with TSHIP) while less than five percent (4.5%) spent more than N20,000 for similar reasons. Overall, the mean or average income spend on admission is N4,113 with the standard deviation of N7,600

Result further shows that few respondents were discharged against medical advice (DAMA) from the hospital in the last one year for financial reasons in hospital other than OAU health centre.

**Table I: Socio-Demographic Data of Respondents**

Variables	Frequency (N=244)	Percentages (%)
<b>Age-group (in years)</b>		
16 - 20	97	39.8
21 - 25	99	40.5
26 - 30	41	16.8
31 - 35	7	2.9
<b>Sex</b>		
Male	103	42.2
Female	141	57.8
<b>Place of Origin/Tribe</b>		
Igbo	4	1.6
Hausa	4	1.6
Yoruba	213	87.3
Others	23	9.5
<b>Level of Students</b>		
100	48	19.7
200	50	20.5
300	87	35.7
400	53	21.7
500	6	2.5
<b>Number of Years Spent in School</b>		
1	42	17.2
2	44	18.0
3	63	25.8
4	38	15.6
5	41	16.8
6	16	6.6

**Table II: Prevalence of SCD among admitted Undergraduates at OAU Health Centre over a five year (July 2010 - June 2015) period**

YEAR	Male with SCD		Female with SCD		Total with SCD		Gross Admission
July -June	Freq.	(%)	Freq.	(%)	Freq. (N=485)	(%) T=21.6	Total (N=2241)
2010-2011	30	34.9	56	65.1	86	13.9	617
2011-2012	29	29.0	71	71.0	100	21.2	471
2012-2013	35	38.5	56	61.5	91	20.8	438
2013-2014	34	38.6	54	61.4	88	24.9	353
2014-2015	52	43.3	68	56.7	120	33.1	362

**Table III: Financial History and Burden among Respondent**

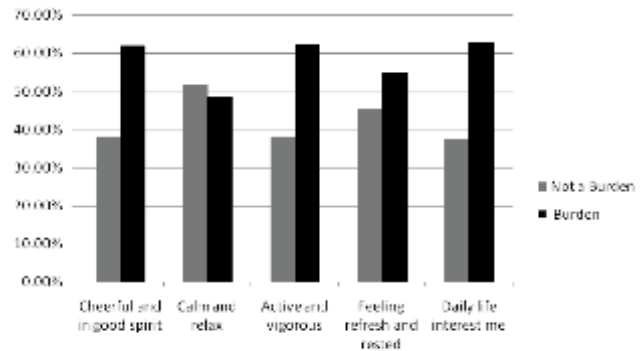
Variables	Frequency (N=244)	Percentages (%)
<b>Sources of income</b>		
Parents	223	91.4
Other family members	10	4.1
Self	6	2.5
Other	5	2.1
<b>Average Monthly Income</b>		
<5000	15	6.2
5000 –10000	61	25.0
10001 –15000	79	32.4
15001 –20000	65	26.6
>20000	24	9.8
<b>Average monthly spending on SCD</b>		
<2500	155	63.5
2500 -5000	42	17.2
5001 -7500	42	17.2
7501 –10000	5	2.1
<b>Average Spending on Admission</b>		
<10000	224	91.8
10000 -<20000	9	3.7
≥20000	11	4.5
<b>Discharge Against Medical Advice for Financial Reasons</b>		
Yes	59	24.2
No	185	75.8

**Table IV: Educational Burden among Respondents**

Variables	Frequency (N=244)	Percentages (%)
<b>Poor Academic Performance</b>		
Yes	164	67.2
No	80	32.8
<b>Outstanding Semester</b>		
None	137	56.2
1	76	31.1
≥ 2	31	12.7
<b>Ever missed a test(s) due to SCD</b>		
Yes	171	70.1
No	73	29.9
<b>Ever repeated a course on account of SCD</b>		
Yes	111	45.5
No	133	54.5

Table IV showed that 67.2% of respondents were of the opinion that SCD contributed to their poor performance. Among those who reported that SCD had negative impact on their performance, 31.1% and 12.7% have 1 or at least 2 outstanding semesters respectively due to SCD. Over two-third of the

respondents reported to have missed test due to SCD and almost half of the respondents reported to have repeated a course on account of SCD



**Fig 1: Reported Psychological Burden by Respondents**

On the average 44.3% of the respondents considered SCD as a psychological burden. Out of these, the forms of Psychological burden identified were difficulty maintaining cheerfulness; being active and having interest in daily life (fig 1).

In table V, the two major socio-cultural variables identified by the respondents, for which they were burdened were being called derogatory name (64.3%) and feeling of not being wanted by significant others (60.7%). A relationship exist between the average monthly income and Socio-cultural Burden of respondents the p-value is 0.007, likewise with their psychological burden (p= 0.016), hence monthly income of respondents interviewed also could play major role in reducing socio-cultural burden of students concerning SCD. The pain severity of respondents interviewed is significantly related to both their psychological burden (p= 0.000) and socio-cultural burden from SCD (p= 0.000)

**Table V: Socio-cultural Burden among Respondents**

Socio-cultural data	Not a Burden		Burden	
	Frequency	Percentages (%)	Frequency	Percentages (%)
Called derogatory names	87	35.7	157	64.3
Health negatively affect relationship with same sex	142	58.2	102	41.8
Health negatively affect relationship with opposite sex	193	79.1	51	20.9
Felt unwanted by family, friends/neighbor	96	39.3	148	60.7
Health states negatively affect family income	169	69.3	75	30.7
Health state affected educational attainment	175	71.7	69	28.3
Average socio-cultural burden	153	62.7	91	37.3

## DISCUSSION

This study contributes to the existing literature on the burden of SCD among the adolescents and young adults who has paucity of literature in the past. More so, the study was on the Obafemi Awolowo University undergraduates who have myriads of psychosocial issues but in these participants the presence of chronic diseases –SCD has further increase their educational challenges.

### Prevalence

The prevalence studied was an indirect measure of the burden of SCD on the health care giver. The national prevalence of sickled hemoglobinopathy in the general population has been estimated to be about 20-30%<sup>7</sup>. The prevalence of SCD among Obafemi Awolowo University undergraduate students using the hospital admission at OAU health centre over a 5-year period was found to be 21.6%. This correlated well with the national prevalence and it explains a lot on the need for the hospital and its management to stem the tide by increasing public awareness.

Male were 42% in the study population. Most SCD patients especially the males do not come to the hospital until they develop unbearable pains<sup>8,9</sup>

The prevalence using the statistics of the registered students could not be used in this study because majority of the students do not complete their registration and even when completed most of the vital information needed for this study i.e genotype and treatment for SCD prior to their admission into the university were also not indicated. The societal attitude towards the clients before admission into the university might be a reason, our religious belief might be a reason as put forward by Harrison 2005 as one of the most important reasons while clients rejects being a SCD patient by faith<sup>10</sup>. Majority do not own up to their SCD status, they are either AA or AS at worst<sup>11</sup>.

### Financial Burden of SCD

The financial burden of the participants of this study has been greatly helped by TISHIP (a form of NHIS) where drug, laboratory investigations and

other hospital care are covered. But they are not resident within the university all year round which explains why 24.2% of them were discharged from hospital other than Obafemi Awolowo University health centre due to lack of fund. The cost of treatment is 10 times higher for patients with SCD under Florida Medicaid Programme<sup>12</sup>. 57.9% have financial burden but we got 24.2% largely due to the effect of TISHIP on the participants in the study<sup>13</sup>. This was also supported by WHO explanation in 2005 of the downward spiralling effects of financial burden on people with SCD<sup>14</sup>

### Educational Burden of SCD

Pain severity significantly affected their educational performance. In the work of Anie published in 2005 which measured the impact of pain and other symptoms on the daily life of individuals with SCD and societal attitude found out that with increase in age, the impact of pain worsen<sup>15</sup>. Similar work by Adegbola in 2011 presented a finding of reduced self efficacy which directly affects performance, confidence and beliefs of control in chronic diseases<sup>16</sup>. This also corresponds well to the findings of 31% of the participants having to repeat a semester while 13% will have to repeat 2 or more semesters and 111 participants out of the 244 studied had one or more courses to repeat.

### Psychological Burden of SCD

The psychological burden was found to be 44.3%, worse among people with severe pain grade, low income earners and higher number of hospital admission. This agrees with the report of the research work by Palermo & Anie in 2002 and 2005 respectively<sup>15, 17</sup>. The number of admission of patients living with SCD significantly correlates with their psychological burden and this agrees with Thompson *et al*, 2005<sup>18</sup>

### Socio-Cultural Burden of SCD

37% of the participants had significant socio-cultural burden which correlates with what Asnani found in his own study based on a strong community support.<sup>19</sup> In the work done by Olagunju *et al* where she found out that the burden of SCD is

greatly reduced by improving the coping mechanism and largely also on improved treatment.<sup>20</sup> It was also reported in the same study that early diagnosis help to reduce all round burden. The continuous improvement in the pain management at Obafemi Awolowo University health centre, the wealth of experience of nurses over the years in management of SCD and prompt availability of drugs and other medications could have contributed to the reduced socio-cultural burden observed.

## CONCLUSION

Subsequent studies on psychosocial problems of SCD should be done with larger samples to fully understand the expectations of affected individuals from their caregivers. The care model used by nurses to assist this group should be assessed for its efficiency and where needed, appropriate model should be adopted

## IMPLICATIONS ON THE FINDINGS

There should be conscious effort by the health maintenance unit of the university to address the needs of undergraduates with HbSS to reduce the burden of SCD on their academic performance. The Social support initiative should be sensitive to their needs, helping them advocate for fewer courses registration per semester as their health may demand, educating the university populace to shun stigmatization and reinforcing the existing Sick cell club. The health centre can have a no-delay service delivery method for these group of people so as to encourage patronage.

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