

STIGMATISING ATTITUDES TOWARDS PEERS WITH SICKLE CELL DISEASE AMONG SECONDARY SCHOOL STUDENTS IN NIGERIA

Bolanle Ola, Rotimi Coker, and Cornelius Ani

Abstract: Sickle cell disease (SCD) is a serious genetic blood disorder experienced by many young people in Nigeria, but the attitudes of students to peers with SCD is scarcely studied. We explored the stigmatising attitudes towards SCD among 370 secondary school students in Nigeria. The students completed questionnaires on attitude to SCD based on a modified Bogardus scale. A significant proportion of the students endorsed negative attitudes towards peers with SCD and showed poor knowledge of the condition. For example, only 41% thought most students would invite a peer with SCD to their birthday party; only 43% thought most students would like to study together with a peer with SCD; 30% believed spiritual and traditional healers can cure SCD; 11% believed that SCD is caused by evil spirits; 15% believed it can be caused by bad food; and 9% thought it is infectious. Regression analysis identified as significant predictors of negative attitudes these two factors: (a) having less personal contact with people affected by SCD, and (b) the belief that people with SCD cannot lead a normal life. Interventions to reduce negative attitudes towards victims of SCD among school children in Nigeria should include more exposure to people with SCD and positive information to challenge nihilistic beliefs about the condition.

Keywords: sickle cell disease, stigma, students, attitude, knowledge, Nigeria

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Sickle cell disease (SCD) is an autosomal recessively inherited disorder and one of the most common genetic conditions worldwide (Weatherall, 2008). It affects mainly people of Afro-Caribbean, Middle Eastern and Asian origins. However, cases are now seen throughout the world due to migration. Nigeria has the highest prevalence of SCD worldwide because it is the most populous Black nation (World Health Organisation, 2006).

The red blood cells of people with SCD develop a sickle-shaped deformity under certain conditions such as low oxygen tension; hence the name of the disease. The main pathology results from deformed red cells being trapped in small blood vessels leading to ischaemia. This typically manifests as acute and or chronic pain especially in the bones and joints. The acute pain, which is more common can be severe and last from hours to days. This “painful crisis” is the most distressing symptom in patients with SCD (Wethers, 2000). The disease is associated with other physical complications, including anaemia, jaundice, infections, stroke, gallstones, and kidney disease (Wethers, 2000). Although recent advances have improved the medical outcome for people with SCD in developed countries, the vast majority of people with SCD live in developing countries where treatment opportunities are more limited (Serjeant, 2005).

While the psychological outcome for people with SCD in developed countries has improved in line with advances in medical care and psychosocial care (Claster & Vichinsky, 2003), the psychosocial outcome in many developing countries remains difficult. For example, a recent study from Nigeria (Bakare, Omigbodun, Kuteyi, Meremikwu, & Agomoh, 2008) found disproportionate rates of psychopathology among children with SCD (38%) compared with healthy controls (11%).

Multiple factors contribute to the outcome of children affected by SCD. Some are related the nature and severity of SCD such as the specific genotype. Others factors are related to the effect of SCD on interpersonal relationships, such as the experiencing by victims of negative attitudes from non-affected persons. For school children with SCD, the attitude of their fellow students toward them is important as stigmatising attitudes could lead to peer rejection and bullying. There is evidence that childhood peer rejection can lead to emotional distress, school avoidance, academic underachievement, and long-term occupational failure in adulthood (Buhs & Ladd 2001). This is why our study focused on the stigmatising attitude of school children toward their peers with SCD.

Empirical investigation of stigma in SCD is growing (Dyson et al., 2010; Jenerette & Brewer 2010; S. Dyson, Atkin, Culley, S. E. Dyson, & Evans, 2011; Dennis-Antwi, Culley, Hiles, & Dyson, 2011), but no studies have explored stigmatising attitudes towards SCD by school children in sub-Saharan Africa – a region with a high prevalence of the condition. Understanding the factors associated with negative attitudes by school children towards SCD could help to develop interventions to improve the experience of affected children in schools. This study aimed to quantify the level and contributory factors of stigmatisation by Nigerian secondary school students towards SCD. We hypothesised that students who have less personal contact with people with SCD and students with limited knowledge of the condition will have more stigmatising attitudes towards SCD.

Methods

We conducted a questionnaire survey of 370 secondary school students in Lagos State, Nigeria. Lagos is the largest city and commercial capital of Nigeria. The students were selected with a multi-stage random sampling technique. The first stage of the sampling involved selecting four secondary schools. The second stage involved random selection of one class in each school from Junior Secondary Classes 2 and 3 and Senior Secondary Classes 1 and 2. Prior discussion with headmasters in the selected schools indicated that sampling from these classes would be least disruptive for the schools. Finally, 20 to 25 students were selected from each class using a table of random numbers and weighted by class size. Following informed consent from parents and the children, the selected children completed the questionnaires privately in their classrooms in a quasi-exam condition. The questionnaire was presented in English, which is the medium of instruction in secondary schools in Nigeria. No parent or child who was selected declined to participate. A total of 378 students were selected but 8 were not in school on the day the questionnaires were administered. The study was approved by the Ethics and Research Committee of Lagos State University Teaching Hospital. Our approach to conducting the study met the requirements of the Helsinki Declaration on the use of human participants in research.

Measurements

Stigmatisation

The students' stigmatising attitude toward peers with SCD was assessed with five questions on social distance modelled after Bogardus Social Distance Scale (Bogardus, 1933). The original Bogardus scale has been widely adapted for different age groups including children (Walker, Coleman, Lee, Squire, & Friesen, 2008) and in different parts of the world including Nigeria (Adewuya & Makanjuola, 2008; Ani, Ola, & Coker, 2011). Vignettes were presented about a hypothetical "boy" in the student's class who suffers from SCD. The students were invited to indicate on a 3-point Likert scale how most students in their school would respond to the vignette. We piloted and adopted vignettes that were more relevant to typical interactions among secondary school students. Unlike previous studies of negative attitudes with respect to mental illness and epilepsy, we avoided vignettes which portray very intimate associations (e.g., willingness to marry someone with a stigmatising condition) as such behaviours are of less direct relevance to children of secondary school age and may cause distress to children with SCD. Also, the active verbs in some of the vignettes were positively framed (e.g., "would" instead of "would not") to minimise potential distress for children with SCD who might be in the sample. We piloted gender-neutral versions of the vignettes and got feedback that they were too impersonal. The pilot showed that the students were not confused by the use of "a boy" in the vignettes. Other studies have successfully used gender-specific vignettes (Walker et al., 2008). The five social distance items were summed to create a social distance scale with a range of 0-10 (higher scores = more stigmatising attitudes, Mean 4.3, *SD* 2.6). The internal consistency was good (Cronbach Alpha = 0.8). The full scale and proportion of responses are shown in Table 1.

Knowledge and beliefs about SCD

The students' knowledge and beliefs about SCD were assessed with eight statements to which the students indicated "yes" or "no" responses. The statements were selected to examine aspects of the biology of SCD (e.g., heritability), variability in outcome (e.g., that some affected persons can lead a "normal" life), and inaccurate perceptions known to be associated with stigma (e.g., the belief that SCD is infectious). The answers were coded "yes" = 0 and "no" = 1. Instead of aggregating the eight questions to create a composite scale of knowledge and belief, we treated each item individually in analysis as we were keen to identify the specific knowledge or beliefs related to negative attitudes. The latter could be used as a target in anti-stigma intervention. The full list of items is shown in Table 2.

Level of personal contact with SCD

The students' level of personal contact with SCD was assessed with the "level of contact report" (Holmes, Corrigan, Williams, Canar, & Kubiak, 1999; Corrigan, Edwards, Green, Diwan, & Penn, 2001). The Level of Contact Report lists seven situations of varying degrees of contact with people affected by SCD. The situations varied from least level of personal contact (1 = "I have never heard of or seen someone with SCD"), to medium personal contact (4 = "I have a friend who suffers from SCD"), to highest personal contact (7 = "I have SCD"). The students were instructed to indicate all of the situations on the 7-item list that they have experienced in their lifetime. The measure of personal contact is the highest ranked (closest personal contact) indicated by the student. For example, a student who ticked two situations from the list "I have never heard of..." (Rank order score = 1), and "I have a brother or sister who suffers from SCD" (score = 6) will receive a score of 6 because "I have a brother or sister who suffers from SCD" is a higher level of personal contact with SCD for this individual student.

Analysis

The data was analysed with SPSS Version 18. Continuous and categorical data were described with Means (and Standard Deviations), and Numbers and Percentages respectively. Scores on the Social Distance Scale were normally distributed; hence T-test was used to conduct bivariate analysis between social distance and dichotomous predictor variables (gender, questions on knowledge and beliefs). Associations between social distance and continuous variables (age, familiarity with SCD, and perceived family attitudes) were explored by calculating Pearson correlation coefficients. Chi-Square tests were used to explore associations between sets of categorical variables such as gender and questions on knowledge. The pattern of missing was random and, as recommended by Pallant (2007), all analyses excluded cases only if they were missing data for the particular analysis. Predictor variables with significant associations with social distance scale were entered simultaneously into a linear regression model to identify independent significant predictor variables.

Results

Of the students, 52% were males and the mean age of the whole cohort was 14 years (SD 1.7, Range 10 to 21 years). Most lived with both parents (88%). There was no significant difference in mean age between males ($M = 14.1$, $SD = 1.63$) and females ($M = 13.9$, $SD = 1.8$); $t(361) = -0.95$, $p = 0.34$. Most of the students were familiar with SCD with 98% having seen or heard of someone with the condition. Male students scored significantly higher on the social distance scale ($M = 4.6$, $SD = 2.5$) than females ($M = 3.9$, $SD = 2.6$; $t(367) = -2.7$, $p = 0.007$). Males also showed significantly poorer knowledge of SCD than females. For example, males were more likely to believe that SCD is infectious (26/163 vs. 7/168; $\chi^2 = 10.5$, $df = 1$, $p = 0.001$) and could be caused by bad food (41/152 vs. 14/160; $\chi^2 = 12.5$, $df = 1$, $p = 0.0001$). They were also less likely to know that SCD affects red blood cells compared with females (28/161 vs. 12/160; $\chi^2 = 5.6$, $df = 1$, $p = 0.018$). There was no significant gender difference on level of personal contact with people with SCD.

Students who believed that SCD can be caused by bad food scored significantly higher on the social distance scale ($M = 5.3$, $SD = 2.4$) than those who did not hold similar beliefs ($M = 4.1$, $SD = 2.6$; $t(364) = 3.2$, $p = 0.001$). Similarly, those who were unaware that the condition is heritable scored significantly higher on the social distance scale ($M = 5.0$, $SD = 2.6$ vs. $M = 4.2$, $SD = 2.6$; $t(365) = -2.0$, $p = 0.045$). Those unaware that the condition affects red blood cells or that some affected persons could lead normal lives also scored higher on the social distance scale ($M = 5.3$, $SD = 2.7$ vs. $M = 4.2$, $SD = 2.6$; $t(358) = -2.8$, $p = 0.006$) and ($M = 5.6$, $SD = 2.8$ vs. $M = 4.0$, $SD = 2.5$; $t(365) = -4.4$, $p = 0.0001$) respectively. The social distance scale correlated significantly and negatively with level of personal contact with SCD ($r = -.20$, $n = 368$, $p = 0.01$).

Table 1 shows the students' responses to the social distance questions. For all five questions, most students endorsed the ambivalent position "not sure". However, a substantial proportion also endorsed negative stigmatising attitudes towards SCD. For example, 35% of the students believed that most students would definitely spread rumours about a peer with SCD. Also, only 41% believed their fellow students would definitely invite such a child to their birthday party and only 43% believed other students would definitely like to do home work together with the affected peer.

Regarding level of personal contact with SCD, most students were familiar with the condition with only 2% stating they had never heard of or seen an affected person; 16% had a relative with SCD and 40% had a friend who has the condition. Four students (1%) identified themselves as having SCD. Most students answered the questions on knowledge correctly. For example, 89% knew that SCD affects red blood cells and 86% knew it is heritable (Table 2). However, a significant minority had inaccurate information. The latter include students who thought that SCD is caused by evil spirits (11%), infectious (9%), caused by bad food (15%), or curable by spiritual healers (30%).

The preceding bivariate analyses identified six explanatory variables with significant positive associations with social distance scale. These are: (a) gender (males had more stigmatising attitude than females); (b) a belief that SCD can be caused by bad

food; (c) being unaware that the condition is heritable; (d) not knowing SCD affects red blood cells; (e) a belief that affected persons could not lead normal lives; and (f) having less personal contact with people affected by SCD. These six predictor variables were entered into a linear regression model to determine if they are significant independent predictors of social distance, controlling for each other as well as age and gender (Pallant 2007).

The ANOVA for the regression model showed it was statistically significant: $F(7, 346) = 6.95, p < 0.0001$. The model showed that (a) a belief that affected persons cannot lead a normal life, and (b) limited personal contact with people affected by SCD were the significant independent predictors of the social distance scale with the latter having a higher beta value ($\beta = -.19, p < 0.0001$) than the former ($\beta = .17, p = 0.002$). The model explained 12.3% of the variance in the social distance scale (see Table 3).

Discussion

To our knowledge, this is the first study to explore the stigmatising attitude of secondary school students towards peers with SCD in sub-Saharan Africa. Despite nearly all the students having some personal contact with people affected with SCD, a significant proportion still had negative attitudes and limited knowledge of the condition. Our finding that less than half of the students believed that their colleagues would do home work with an affected child or would invite the child to their birthday party suggests a significant level of negative attitudes towards SCD in secondary school students in this setting.

The study showed that more personal contact with people with SCD and awareness that some affected persons can lead a “normal life” were the two significant predictors of a less stigmatising attitude. Lack of other similarly-designed studies in SCD means that direct comparison with our study is not possible. However, the findings are consistent with other studies showing high levels of stigma by students against other physical conditions like epilepsy. For example, Njamnshi and colleagues found that 25% of students in Cameroon would not associate with a child with epilepsy (Njamnshi, Angwafor, Jallon, & Muna, 2009). Incidentally, another study of secondary school students’ attitude towards epilepsy in Nigeria using the same format as our current study found that 41% of students believed their colleagues would definitely spread rumours about a peer with epilepsy and only 24% and 31% believed their colleagues would invite this peer with epilepsy to their birthday party or do home work together with him respectively (Ani et al., 2011). This suggests that in this setting, epilepsy appears even more stigmatised by secondary school students than SCD.

Level of contact with SCD and stigmatising attitude

Consistent with our hypothesis, a closer level of contact or familiarity with people affected with SCD was associated with a less stigmatising attitude. The level of familiarity with SCD was high among the students with only 2.4% indicating they had not had any contact with an affected person. However, it is significant that despite the widespread contact with persons with SCD, this does not readily translate into better

attitudes towards people with SCD. Familiarity with the disease is not enough to affect behaviour. Only a closer level of personal association seems to mitigate against a stigmatising attitude.

This finding is similar to other studies of stigma by children against mental illness and physical disorders and consistent with the “contact hypothesis” of stigma (Hebl, Tickle, & Heatherton, 2000). For example, in a study of attitude towards mental illness among young people in Australia, Jorm and Wright (2008) found that exposure to mental disorders was associated with reduced social distance. Njamnshi and colleagues also found that better acquaintance with epilepsy on the part of the subject students was associated with less negative attitude (Njamnshi et al., 2009).

In the context of SCD, our finding suggests that anti-stigma interventions in schools could be more effective if the delivery were to involve improved contact with people who are affected by SCD, for instance through peer education. Evidence from other disorders suggests that such peer education can be effective (Paxton, 2002). In designing such intervention, it should be noted that the quality of interpersonal contact with people with the stigmatised condition may be more important than the quantity. In particular, close social and personal contact may result in better acceptance and reduction in stigma than formalised contact (Hebl et al., 2000). Reduction in stigmatising attitudes from increased personal contact with stigmatised persons works by humanising the affected individuals and highlighting that possession of the stigmatising attribute is only one aspect of the person (Biernat & Dovidio, 2000).

Knowledge and stigmatising attitude towards SCD

Knowledge of SCD among the students was high. For example, 89% knew that SCD affects red blood cells and 86% were aware the condition is heritable. However, one particular aspect of knowledge (that some affected persons can lead a normal life) was predictive of less stigmatising attitude towards SCD. This finding is significant. Although SCD is a potentially serious illness, the natural course is variable and some affected persons (e.g., people with HbSC genotype) can lead a relatively healthy life. Also improved medical care can result in prolonged good health. Therefore an adverse course of SCD characterised by chronic disabling ill health is not inevitable. This type of knowledge could be used in interventions to challenge the type of therapeutic nihilism shown here and in other studies (Gonzalez-Torres et al., 2007) to drive negative attitudes. Although improving knowledge to dispel myths about stigmatising conditions are generally helpful in reducing negative attitudes (Hebl et al., 2000), supplanting specific untruths such as therapeutic nihilism can be particularly helpful (Gonzalez-Torres et al., 2007).

Limitations

This study is the first to measure stigmatising attitudes on the part of secondary school students towards SCD in sub-Saharan Africa. However, the results should be considered with some limitations in mind. The first limitation is that our measure of social distance assesses attitude rather than actual behaviours. Also, attitudinal measures

of this kind are limited by socially desirable responding. Thus, it is uncertain whether the students' responses would match their behaviour in practice. Given that the sample was drawn from secondary schools in a highly urbanised part of Nigeria, caution is advised in generalising the findings to other parts of sub-Saharan Africa or beyond. Finally, the cross-sectional design means no causal inferences can be implied by any of the significant associations found in the study.

Conclusion

The results support our hypotheses and are consistent with well-established stigma theories and previous studies of stigma with respect to other disorders. Our study showed significant levels of negative attitude by students towards SCD. Less stigma was predicted by more contact with SCD and awareness that some affected persons can lead a normal life. SCD can be a challenging condition in developing countries like Nigeria; hence efforts to reduce the additional burden engendered by stigma would be in the interest of affected children. This study provides useful information that could inform the design of effective anti-stigma interventions in secondary schools in Nigeria.

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Tables

Table 1. Social distance questions

Vignette	No, Definitely N (%)	Unsure N (%)	Yes, definitely N (%)
Most students would spread rumour about a boy with sickle cell disease when he is not there:	103 (27.8)	139 (37.6)	128 (34.6)
Most students would invite a boy with sickle cell disease to their birthday party:	61 (16.5)	157 (42.5)	151 (40.9)
Most students would like to do their home work together with a boy with sickle cell disease:	46 (12.5)	165 (44.7)	158 (42.8)
Most students would say bad things to a boy with sickle cell disease:	153 (41.4)	153 (41.4)	64 (17.3)
Most students would like to share food and drinks with a boy with sickle cell disease:	102 (27.6)	167 (45.1)	101 (27.3)

Table 2. Knowledge and beliefs about sickle cell

Variable	Yes N (%)	No N (%)
Sickle cell disease can be caused by evil spirits, witches and wizards.	41 (11.1)	328 (88.9)
Some people with sickle cell disease can lead a “normal” life.	308 (83.7)	60 (16.3)
Spiritual and religious healers are very good at curing sickle cell disease.	105 (29.7)	249 (70.3)
Sickle cell disease is infectious and can be acquired by staying very close to a sufferer.	33 (9.1)	331 (90.9)
People with sickle cell can be very tall compared to people not affected.	119 (33.1)	240 (66.9)
Sickle cell can be caused by bad food.	55 (15.0)	312 (85.0)
Sickle cell disease can be inherited.	316 (86.3)	50 (13.7)
Sickle cell disease affects red blood cells.	321 (88.9)	40 (11.1)

Table 3. Regression coefficients for independent predictors of social distance

Model		Unstandardized Coefficients		Standardized Coefficients	
		B	Std. Error	Beta	t
Model 1	Constant	7.21	1.23		5.88**
	Age	-0.10	0.08	-.06	-1.25
	Gender	0.50	0.27	.09	1.85
	SCD caused by bad food	-0.68	0.39	-.09	-1.75
	SCD can be inherited	-0.29	0.43	.04	0.69
	SCD affects red blood cells	0.69	0.48	.08	1.44
	Affected person can lead normal life	1.17	0.37	.17	3.19*
	Level of personal contact with SCD	-.44	0.12	-.19	-3.73**

* $p < 0.01$, ** $p < 0.001$

Gender coded 1 = Male, 0 = Female

R Square = 0.123