ORIGINAL ARTICLE

Emotional Disorders and their Sociodemographic Correlates among Children and Adolescents Living with Sickle Cell Disease

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ABSTRACT

Background: North-Eastern Nigeria has high birth rates, low literacy levels and low rates of premarital screening for haemoglobin genotype. This probably explains the high prevalence of sickle cell disease (SCD) among children and adolescents. SCD is a chronic disease associated with high rates of co-morbid mental health disorders affecting both the sufferers and caregivers. Despite this burden, there are very few studies that evaluated mental health disorders among people living with SCD in this region. **Objectives:** To determine the prevalence of depression, suicidality, and anxiety among children and adolescents with SCD and the sociodemographic correlates associated with them. **Methods:** This was a single-centre, hospital-based, cross-sectional study conducted at the University of Maiduguri Teaching Hospital. Children and adolescents with SCD were recruited for the study and issued a pretested sociodemographic questionnaire (Kiddie-Schedule for Affective Disorders and Schizophrenia for School-Aged Children Present and Lifetime Version [K-SADS-PL]). Data was analysed using SPSS version 20. **Results:** There were a total of 165 participants with a mean age of 11.2 ± 3.2 years comprising 83 (51.9%) males. Majority (98.1%) had only primary education, and most (83.8%) reside in an urban area. About 77% were diagnosed to have SCD before the age of 8, and 57.5% have received care for more than 5 years. Emotional disorders were present in 53.1% of the participants. These consist of anxiety disorder 38.1%, separation anxiety 28.8%, depression 20.6%, agoraphobia 13.1%, suicidality 5%, panic disorder 3.8%, social phobia/ specific phobia 3.1%, and general anxiety disorder 2.5% respectively. Statistically significant association (P<0.005) was found between emotional disorders and monogamous families, and parents' occupation, **Conclusion:** There is a high prevalence of emotional disorders amongst children and adolescents living with sickle cell disease attending clinics in Maiduguri, which correlated with monogamous family structure, low socioeconomic status. Routine screening for emotional disorders among children and adolescents living with chronic disorders attending the paediatric clinic should be considered and psychosocial support should be provided.

Key words: Emotional disorders, sickle cell disease, Nigeria

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Introduction

Sickle cell disease (SCD) is a chronic debilitating illness of public importance globally.[1,2] Annual global data shows that approximately 330,000 infants are born with SCD. This figure is projected to reach 400,000 by the year 2050.[3] Nigeria bears a huge burden of the global SCD scourge, with an annual incidence of 2 - 3% (i.e. approximately 150,000 infants born with the disease each year)[4] and an estimate of 2-3 million persons suffering from SCD.[3,5] The significant morbidity and mortality associated with SCD and its adverse psychosocial impact on patients and their families make SCD a significant public health challenge in Nigeria.[6,7] The psychological

impact suffered by patients living with SCD is under-recognized and usually not treated. Pain is the most common symptom reported, and it is associated with most of the complications suffered by patients living with SCD.[8,9] Children and adolescents with sickle cell disease (CASCD) are prone to emotional problems, especially depression and anxiety, as they experience repeated painful crises, and occasionally, life-threatening.[10–12] The emotional response of the individual to having SCD and the direct effect of SCD on brain function infers the illness and its consequences in the individual's life. Evidence has shown that the presence of depressive and anxiety symptoms may affect improvement and may worsen pain symptoms.[13–15] In addition, depressed moods and negative thoughts can make it more difficult for people with SCD to cope with pain. Patients with more depressive symptoms experience severe and more frequent acute vaso-occlusive pain crisis.[14,16,17] There is a reciprocal relationship between pain and depression, as pain may also increase the risk of having depression.[12,16,18] Depression has been reported to be the commonest of the emotional problems experienced by persons with SCD. Factors that explain the presence of emotional disorders in children with SCD may include poor adherence to medication, increased hospital follow-up visits, decrease in levels of immunity, recurrent hospitalization, and increased cost of care, poor quality of life and generally poorer outcome.

Methods

Study design

The study was a hospital-based, cross-sectional study to assess the prevalence of emotional disorders among children and adolescents with SCD attending haematology clinics in the UMTH

Study setting and participants

The study was conducted in the paediatric SCD clinic and the haematology day care clinic of UMTH.

Study instruments

The Kiddie-Schedule for Affective Disorders and Schizophrenia for School-Aged Children Present and Lifetime Version (K-SADS-PL) questionnaire is a semi-structured interview for assessing psychiatric disorders in children and adolescents.[1] It assesses current and past episodes of psychopathology in children and adolescents. It is designed for interviewing both parents and children and has been adapted to the DSM-IV diagnostic criterion

Data analysis

The data collected were analysed using the Statistical Package for Social Sciences, version 20.0 software (SPSS-20). Descriptive analysis of the data using frequencies, cross-tabulations and charts was done. Numeric variables were presented as mean ± standard deviation. The association between the socio-clinical variables with depression, suicidality and anxiety was determined using McNamar's test, Chi-square, or Fisher's exact test, where appropriate. Significant variables at bi-variate analysis were subjected to multivariate analysis (logistic regression) to assess the independent predictors of depression, suicidality, and anxiety. The association of age at disclosure with the prevalence of depression, suicidality, and anxiety was determined using the Chi-square. The chi-square test was also used to compare the relationships between emotional disorder with socio-demographic and clinical variables. Statistical significance was set at $p = < 0.05$

Results

There were 160 participants with a mean age of 11.2 ± 3.2years comprising 83 (51.9%) males. A majority (98.1%) had only primary education, and most (83.8%) reside in an urban area. About 77% were diagnosed to have SCD before the age of 8, and 57.5% received care for more than 5 years. Other findings are shown in Table 1.

As shown in Table 3: Emotional disorders were present in 53.1% of the participants. These consist of anxiety disorder 38.1%, separation anxiety 28.8%, depression 20.6%, agoraphobia 13.1%, suicidality 5%, panic disorder 3.8%, social phobia/ specific phobia 3.1%, and general anxiety disorder 2.5% respectively.

Statistically significant association (P<0.005) was found between emotional disorders and monogamous families (see Table 4),

Table 1: Sociodemographic variables of the participants

	SCD N=160 n(%)
Age	
<14	117(73.1)
14-18	43(26.9)
Gender	
Male	83(51.9)
Female	77(48.1)
Educational level	
Below Secondary	157(98.1)
Post-Secondary	3(1.9)
Which of your parent(s) are alive?	
None/Father/Mother	5(3.1)
Both alive	155(96.9)
Do you live with your parent(s)?	
Yes	159(99.4)
No	1(0.6)
Family type	
Monogamous	97(60.6)
Polygamous	63(39.4)
Family size	
Small (≤7 members)	108(67.5)
Large (>7 members)	52(32.5)
Parents Occupation	
Elementary/Trade	120(75.0)
Semi-skilled/higher level	40(25.0)
Area of Residence	
Rural	26(16.2)
Urban	134(83.8)
Family support	
Supportive	160(100.0)
Non-supportive	-
Relationship with parents	
Cordial	160(100.0)
Non-cordial	-
Family history of mental illness	
Yes	-
No	160(100.0)

Table 2: Clinical and laboratory parameters of the participants.

	SCD N=160 n(%)
No. of Admissions	
<3 times	85(53.1)
≥3	75(46.9)
Duration of Treatment	
≤ 5years	68(42.5)
> 5 years	92(57.5)
Child Awareness of Disease	
Yes	145(90.6)
No	15(9.4)
Age at Awareness	
<8 years	112(77.2)
≥8years	33(22.8)
Routine Medication	
Folic acid/ paludrine	160(100.0)
Other medications	
Medication Adherence	
Yes	160(100.0)
No	-
PCV (Levels of Anaemia)	
Mild	6(3.8)
Moderate	120(75.0)
Severe	34(21.2)

**PCV packed cell volume*

Table 3: Prevalence of emotional disorders

	SCD N=160 n(%)
Emotional disorders	
Yes	85(53.1)
No	75(46.9)
Depression	
Yes	33(20.6)
No	127(79.4)
Suicidality	
Yes	8(5.0)
No	152(95.0)
Any anxiety disorders	
Yes	61(38.1)
No	99(61.9)
Panic disorder	
Yes	6(3.8)
No	154(96.2)
Social Phobia	
Yes	5(3.1)
No	155(96.9)
Specific phobia	
Yes	5(3.1)
No	155(96.9)
Agora phobia	
Yes	21(13.1)
No	139(86.9)
Separation Anxiety	
Yes	46(28.8)
No	114(71.2)
GAD	
Yes	4(2.5)
No	156(97.5)

*GAD = Generalized Anxiety Disorder

Table 4: Association between sociodemographic parameters and emotional disorders

	Any emotional disorder **N=85** **n(%)**	**No emotional disorder** **N=75** **n(%)**	**χ^2 (ᵞ)**	**P-value**
Age (years)				
<14	60(51.3)	57(48.7)	0.594+	0.447
14-18	25(58.1)	18(41.9)		
Gender				
Male	41(49.4)	42(50.6)	0.962+	0.327
Female	44(57.1)	33(41.9)		
Educational level				
Below Secondary	83(52.9)	74(47.1)	0.225 (0.000)	0.635 (0.999 ᵞ)
Post-Secondary	2(66.7)	1(33.3)		
Which of your parents are alive?				
None/Father /Mother	2(40)	3(60)	0.357 (0.020)	0.550 (0.887 ᵞ)
Both	83(53.5)	72(46.5)		
Do you live with your parents?				
Yes	85(53.5)	7446.5)	1.140 (0.020)	0.286 (0.887 ᵞ)
No	-	1(100)		
Family type				
Monogamous	58(59.8)	39(40.2)	4.400	**0.036* (0.053 ᵞ)**
Polygamous	27(42.9)	36(57.1)		
Family size				
Small (≤7 members)	60(55.6)	48(44.4)	0.788	0.375
Large (>7 members)	25(48.1)	27(51.9)		
Parents Occupation				
Elementary/Trade	66(55)	54(45)	0.678	0.41
Semi-skilled/higher level	19(47.5)	21(52.5)		
Area of Residence				
Rural	16(61.5)	10(38.5)	0.882	0.348
Urban	69(51.5)	65(48.5)		
Family support				
Supportive	85(53.1)	75(46.9)	-	-
Non-supportive	-	-		
Relationship with parents				
Cordial	85(53.1)	75(46.9)	-	-
Non-cordial	-	-		

Family history of mental illness				
Yes	-	-	-	-
No	85(53.1)	75(46.9)		

Table 5: Association between disclosure of SCD status with emotional disorders

	Depression N=33 n(%)	**No Depression N=127 n(%)**	**χ^2 (ᵞ)**	**P-value**
Child Awareness of Disease				
Yes	32(22.1)	113(77.9)	1.97 (1.141)	0.160 (0.285 ᵞ)
No	1(6.7)	14(93.3)		
Age at Awareness				
<8 years	26(23.2)	86(76.8)	0.375 (0.140)	0.540 (0.709 ᵞ)
≥8years	6(18.2)	27(81.8)		
	Suicidality N=8 n(%)	**No Suicidality N=152 n(%)**	**χ^2**	**P-value**
Child Awareness of Disease				
Yes	8(5.5)	137(94.5)	0.871 (0.091)	0.351 (0.756 ᵞ)
No	-	15(100)		
Age at Awareness				
<8 years	4(3.4)	108(96.4)	3.574 (2.122)	0.059 (0.145 ᵞ)
≥8years	4(12.1)	29(87.9)		
	Any emotional disorder N=85 n(%)	**No emotional disorder N=75 n(%)**	**χ^2**	**P-value**
Child Awareness of Disease				
Yes	78(53.8)	67(46.2)	0.277	0.599
No	7(46.7)	8(53.3)		
Age at Awareness				
<8 years	62(55.4)	50(44.6)	0.484 (0.065)	0.486 (0.799 ᵞ)
≥8years	16(48.5)	17(51.5)		
	Any anxiety disorder N=61 n(%)	**No anxiety disorder N=99 n(%)**	**χ^2**	**P-value**
Child Awareness of Disease				

Yes	55(37.9)	90(62.1)	0.025 (0.000)	0.875 (0.999 ٧)
No	6(40)	9(60)		
Age at Awareness				
<8 years	43(38.4)	69(61.6)	0.045	0.833
≥8years	12(36.4)	21(63.6)		

Discussion

In this study, the prevalence of emotional disorders among CASCD is found to be relatively high (53.1%). However, Bakare et al.[8] found a lower prevalence of emotional disorder of 37.8% among children with SCD. Furthermore, a lower prevalence of 19% was reported by Hijman et al.[13] among CASCD aged 6-18 using internalizing behaviour component of the Child Behaviour Checklist. This prevalence was based on symptoms reported by caregivers and teachers, respectively. The frequency of multiple admissions (>3 admissions) was high among our study participants (46.9%) which was found to be significantly associated with the presence of emotional disorders in the participants. Just like previous studies, this finding entails those children and adolescents (including their parents) with more frequent and repeated hospitalizations are likely to have more psychological distress than those with fewer hospitalizations.

Although a majority (51.9%) of the study participants were male, this was not significantly associated with the presence of emotional disorders among the study participants. Bakare et al.[8] in South-Western Nigeria found a similar gender distribution of children with chronic illness. The mean age of the participants was 11.4 years, with about half (52.5%) of the participants being in the early adolescent (10-14 years) category. In contrast to our findings, Bakare et al.[8] reported a slightly higher mean age of 13.76 ± 2.74 although their study had a significantly smaller sample size (of 45 participants).

Among the CASCD in this study, the prevalence of depression was 20.6%. This finding is slightly lower than the prevalence of depression of 29% among persons with SCD reported by Burlew et al.[15] However, the study's authors mentioned above used a different instrument (Beck's Depression Inventory). Moreso, older adolescents aged 14-19 years constituted their study population compared to 6-18 years in this study. A 2016 systematic review by Jonassant and colleagues.[16] found the prevalence of depression to be 25%-46%. This systematic review comprised of both children and adults, which may explain the vast disparity. Jerell[17] reported a higher prevalence of 46% among the same population of patients. Lukoo in 2015,[18] reported a prevalence of 86.4% among CASCD aged 8-17 years. In Nigeria, Ohaeri[19] in 1995 and Anie[20] in 2010 also reported higher 55% and 54% rates, respectively. However, the prevalence mentioned above rates were based on depressive symptoms rather than diagnosis, and the age range was wide, adult SCD participants were included in both studies.

On the contrary, the prevalence in our study was higher than the rate of 13% reported by Sehlo et al.[21] in 2015 who considered adolescents aged 10-15, which may explain the relatively low prevalence. In addition, a review by Benton et al.[22] on children and adolescents with SCD reported the prevalence of depression to be 12.5%. However, there was variation in sample size and methodology.

The backwardness in education among CASCD in our study is not unexpected. Laurence et al.[23] found that CASCD with depression is more likely to have a lower level of education. This may be due to missed classes because of any one or more of the following: painful crisis, recurrent hospitalization, blood transfusion, and opportunistic infections. The Boko Haram insurgency in north-eastern Nigeria has caused most public schools in Maiduguri to be used as internally displaced persons (IDP) camps, thereby affecting most schools' academic calendars.

In this study, the prevalence of suicidality among children and adolescents with SCD was 5%. This finding is unexpected. Most studies reported higher prevalence of suicidality among CASCD compared to our study. For instance, Omigbodun et al.[24] conducted a study in Nigeria among youths aged 10-17 years and reported the prevalence rate of suicidality to be 20%. This huge difference could be explained by the age selection (10-17) of their study, which means that most of the participants have

developed cognitive ability to understand the nature of their problems. In addition, their sample size was large and can give a better picture. Lukoo et al.[18] in 2015 reported a prevalence of 23.5% among CASCD aged 8-17 years. This disparity could be explained based on the use of the different instruments and a lesser sample size. Furthermore, 20% and 11% suicidality were reported by Bakare et al.[8] in a study of children and adolescents with sickle cell disease and Juvenile Diabetes Mellitus (JDM), respectively. The wide disparity range may be due to the different instruments and small sample size. Furthermore, the difference in the sociocultural and religious peculiarities between northern Nigeria (where our study was conducted) and that of the southern Nigeria (where the study by Omigbodun et al.[24] and Bakare et al.[8] were carried out) could also partly explain the variation.

In this study, the prevalence of anxiety among participants with SCD is 38.1%. Cepeda et al.[25] studied CASCD aged 6-19 years and reported the prevalence of anxiety disorder to be 10 %. However, their sample size was small (39 participants) compared to our study (160 participants). Benton et al. [22] 2011 reported a lower prevalence of 15% among adolescents with SCD aged 12-19 years. Unlike our study, they only considered adolescents aged 12-19 years with a small sample of 40 participants. Anie et al.[26] reported a prevalence of anxiety to be seven per cent, but the study was based on symptoms (anxiety feelings).

Nearly two-thirds of the participants (60%) are from a monogamous family setting. This finding is unexpected as polygamous settings are more common in northern Nigeria due to cultural and religious beliefs. [9] It may be as a result of economic considerationsoccasioned by the economic downturn being experienced in the country during and prior to the study period; that people no longer practise polygamy as frequently as in the past. In addition, Acculturation with improvement in western education and awareness may contribute to this practice. In addition, most of the participants have a small family size of fewer than seven persons. This observation agrees with the findings of the United Nations Development Programme survey that reported the average household size in the northeast is seven.[9]In contrast to family size, which was not significantly associated with presence of emotional disorders, family type (being polygamous or monogamous family) was significantly (P = 0.036) associated with, in this study.

All the SCD participants (100%) were on folic acid and paludrine as routine medications. This finding may highlight the physicians' preference for medication regimen, which may have improved the healthy period among SCD participants. Fey et al[10] reported that people with SCD have less optimal folate status than their healthy counterparts. In addition, a Cochrane review concluded that the use of folic acid in children with SCD improves folate storage.[11] The use of paludrine as a prophylaxis for malaria, which is endemic in the study location, may also improve the healthy period of the SCD participants. About two-thirds of the participants (75%) in the SCD group recorded a PCV of 26%-36% that depicts moderate anaemia while 34 participants (21.2%) recorded PCV that depicts severe anaemia (<26.7%). This finding is within the range of the average PCV found among SCD patients reported in Maiduguri.[12] This may reflect the pattern of the steady state PCV among the SCD participants in this part of the world.

In conclusion, there is a high prevalence of emotional disorders amongst children and adolescents living with sickle cell disease attending clinics in Maiduguri, which positively correlated with monogamous family structure, low socioeconomic status and depression. Routine screening for emotional disorders among children and adolescents living with chronic disorders attending the paediatric clinic should be considered and psychosocial support should be provided.

Limitations of this study include the study was cross-sectional and causal relationships could not be established. Psycho-trauma may have a confounding effect as the study area has been ravaged by the Boko haram insurgency for over a decade.

Author contribution

All authors contributed in the research and writing of this article.

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Conflict of interest

The authors declare none

Ethical approval and consent to participate

Approval for the study was obtained from the ethics and research committee UMTH prior to commencement of the study. The research was performed in accordance with the Declaration of Helsinki.

Consent to participate

All participants gave written informed consent before taking part in the study

Availability of data and material

All datasets can be made available from the corresponding author on request

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