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Psychosocial Complications in Sickle Cell Anaemia

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Author's contribution

The sole author designed, analysed, interpreted and prepared the manuscript.

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ABSTRACT

Introduction: Adolescents with sickle cell anaemia (SCA) are challenged by a myriad of complex psychosocial issues which may arise as complications of living with the disorder. The magnitude of these psychosocial adjustment issues is scarcely being assessed, as more focus is often given to the physical symptoms and signs of SCA.
Objectives: This study sought to assess the prevalence of psychosocial complications (depression, avoidance of the health care system, social withdrawal and suicidal ideation) in adolescents with SCA in steady state, seen at the University of Port Harcourt Teaching Hospital (UPTH) and to compare this with the prevalence of same psychosocial complications in non-SCA controls matched for age, gender and socioeconomic class.
Methodology: Using a cross-sectional design, 200 adolescents with SCA (subjects) were recruited consecutively from the Paediatric Haematology Clinic of UPTH. Controls matched for age, gender, and socio-economic class, with haemoglobin genotype AA or AS were recruited from the Children Outpatient Clinic of UPTH. A self-administered questionnaire was used to obtain the clinico-demographic and psychosocial data.
Results: There were 97 (48.5%) males and 103 (51.5%) females in each group with a male to female ratio of 1:1.1. One hundred and fifty-eight (79.0%) subjects had a depressive feeling compared to 15 (7.5%) in the control group. One hundred and twenty two (61.0%) subjects avoided the health care system compared with 10 (5%) among the controls. Thirty nine (19.5%) subjects had social withdrawal compared with eight (4%) among the controls. Seventeen (8.5%) subjects

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had suicidal ideation compared with none among the control group. The prevalence of all four psychosocial complications assessed was significantly higher in the subjects compared with the controls.

Conclusion: Psychosocial complications are a major problem among adolescents with SCA. Regular psychosocial assessment is recommended for every SCA patient on follow up. Early detection and prompt psychological interventions are key to improving the quality of life in affected persons.

Keywords: Psychosocial effects; sickle cell anaemia.

1. INTRODUCTION

Sickle cell anaemia (SCA) is one of the most common genetic diseases worldwide [1] and in Nigeria [2]. The World Health Organisation (WHO) reported in the fifty-ninth World Health Assembly that nearly 300,000 infants each year are born with major haemoglobin disorders in Africa, with more than 200,000 cases of SCA [3]. Nigeria has the highest burden of SCA with 20 out of every 1000 births [3]. A significant proportion of children with SCA require frequent medical attention and hospitalisations for symptoms that may begin as early as six months of age [4]. They may also develop recurrent infections and severe complications such as splenic sequestration, organ damage, stroke, and priapism [4]. As they approach the adolescent age, they may, in addition, experience delayed puberty, leg ulcers, and avascular necrosis of the hip and shoulder [4].

The frequent clinic appointments may disrupt schooling, employment and other social activities, hence posing both medical and psychosocial challenges to the affected individual and their families [4]. Whereas the psychological outcome of people with SCA in developed countries has improved in line with advances in medical and psychosocial care, the psychosocial outcome in many developing countries remains poor [5].

Individuals with SCA have many physical and psychological challenges they contend with in their daily lives [6]. In adolescence, these challenges have been seen to contribute to isolation, depression, ineffective coping, and feelings of stigmatisation due to poor peer relationships [6]. These emotional changes have been shown to exacerbate the symptoms of the disease [6] hence, adding more strain on their healthcare management [4]. Some researchers have even proposed that persons with SCA be taught positive coping strategies which are beneficial in the management of chronic diseases [6,7].

Depressive symptoms are very common in patients with chronic health conditions [8]. It can be a result of the constant demands of the illness or intrusive treatments. It can also be as a result of societal stigmatization [8] Likewise, Iloeje [9] in Eastern Nigeria found parent-rated psychiatric morbidities in 26.6% of children with SCA compared with 4.8% of healthy matched controls. Another study from Nigeria by Bakare et al. [10] also showed significantly more psychological difficulties among children with SCA (38%) compared with controls with no chronic illness (11%).

The demands of frequent ill health and stigmatising attitudes from the public may lead to decreased school or work productivity and absenteeism, which significantly impacts on the social network of these adolescents with SCA [11]. This leads to social isolation, limited peer interaction, lack of experience with problem resolution skills and consequently, social withdrawal [11].

Suicidal ideations and thoughts are very common among patients with depression, chronic illnesses and chronic severe pain [12]. Studies [13,14] have indicated that suicide is also one of the causes of death among SCD patients. This may be due to the severity of the pain they experience, the economic burden of treatment, stigmatisation or poor psychosocial adjustment [13]. This study, therefore, sought to assess the prevalence of psychosocial complications (depression, avoidance of the health care system, social withdrawal and suicidal ideation) in adolescents with SCA in steady state, seen at the University of Port Harcourt Teaching Hospital (UPTH) and to compare this with the prevalence of same psychosocial complications in non-SCA controls matched for age, gender and socioeconomic class.

2. MATERIALS AND METHODS

This was a hospital based cross sectional study done over a period of nine months (March 2018 to December 2018). The study population consisted of two groups, 200 subjects and 200 controls. The subjects were adolescents aged 10 to 18 years with SCA in steady state who came for follow up at the Haematology Clinic of the Department of Paediatrics, UPTH. The controls were adolescents aged 10 to 18 years with HbAA or HbAS genotype matched for age, gender and socio-economic class with the study subjects recruited from the Children Outpatient Clinic of the Department of Paediatrics, UPTH.

The researcher did a one-month posting in the Department of Mental Health, UPTH during which skills in conducting a psychological interview were acquired. The skills include a non-judgemental approach to interviewing patients, avoiding the use of derogatory words, and keen observation of non-verbal cues expressed by respondents. Two research assistants, who were resident doctors in paediatrics, were trained and supervised by the researcher on the study protocol and how to fill out the questionnaires in a two-day training work-shop. A self-administered questionnaire was used to derive psychosocial data.

Social withdrawal was assessed using a six-item scale that has good internal consistency (Cronbach's alpha- 0.90) [15]. The items were scored on a scale of 1 to 4 ('strongly disagree' to 'strongly agree'). A sum of all the scores for each respondent was obtained. The total scores ranged from 6 to 24. Scores $\geq$ 15 were labelled 'Social withdrawal present' and scores < 15, 'Social withdrawal absent' (Cronbach's alpha - 0.90).

Avoidance of the health care system referred to any deliberate delay or reluctance in seeking a health service even when it has become necessary [16].

Depressive feeling referred to any feeling of extreme sadness, hopelessness, helplessness, worthlessness, self-hate or inappropriate guilt [17].

Suicidal ideation referred to thinking about or having an unusual preoccupation with suicide. It ranged from fleeting thoughts to detailed planning and incomplete attempts [14].

The questionnaires were self-administered, however, some respondents demanded further explanations and as such were assisted by the researcher and assistants.

Each filled questionnaire was reviewed by the researcher to ensure it was properly filled and to identify patients who would need further counselling and/or referral.

The scales in the questionnaire had been face and content-validated by a specialist in mental health. The study questionnaire was also pretested before the study was commenced. The pre-test was conducted using 10% of the targeted sample size (20 subjects and 20 controls) at the same study site. This allowed the researcher and assistants pre-test the research tool and get properly acquainted with the study protocol. No major changes were however made to the research materials following the pre-test. The results from the pre-test were not included in the main study.

The principles of the Helsinki Declaration were respected as follows:

Confidentiality: All patient information was kept confidential and participants' identity during data collation was completely anonymous.

Beneficence: All patients in the study population were given an equal chance to participate. Counselling was done for subjects with psychosocial complications before referral for specialised care. Free haemoglobin genotype testing was done for participants in the control group whose genotypes were yet to be ascertained.

The data was analyzed using SPSS version 20.

3. RESULTS

A total of 400 adolescents, comprising 200 adolescents with SCA (subjects) and 200 controls matched for age, gender, and socioeconomic class were enrolled into this study over a period of nine months.

3.1 Socio-demographic Characteristics of the Study Population

The age and gender distribution of the study subjects and controls are shown in Table 1. The mean age of subjects was 13.79 $\pm$ 2.45 years while that of the controls was 13.94 $\pm$ 3.26 years. The difference in age was not statistically

significant (t= 0.329, p= 1.000). There were 97 (48.5%) males and 103 (51.5%) females in both groups, with a male to female ratio of 1: 1.1. Most (99.5%) of the respondents were Christians.

3.2 Educational Status and Family Social Class of Study Subjects and Controls

Overall, 296 (74.0%) participants were in secondary school, while 104 (26.0%) were in primary school. One hundred and ninety-six (49.0%) participants were of high social class, 140 (35.0%) were middle class and 64 (16.0%) of low social class. The educational level and family social class distribution are shown in Table 2.

Fig. 2 shows the prevalence of a depressive feeling, avoidance of the health care system, social withdrawal, and suicidal ideation in subjects and controls. A depressive feeling was significantly higher in the subjects, 158 (79.0%) than in the controls, 15 (7.5%) (p = 0.001). One hundred and twenty-two (61.0%) subjects avoided the health care system compared to 10 (5.0%) controls (p = 0.001). Social withdrawal was present in 39 (19.5%) subjects compared to 8 (4%) controls (p = 0.014). Seventeen (8.5%) subjects and none of the controls had suicidal ideation (p = 0.011).

4. DISCUSSION

Seventy-nine percent of the subjects in this study admitted to having a depressive feeling compared to 7.5% in the control group. This is in agreement with the reports of Ola et al. [19] in Lagos who reported a prevalence of 71.8% in 2016. The prevalence is higher than the reports of between 43-56% by other researchers [8,17]. The observed higher prevalence in this present study might be due to the method used in the assessment. While this present study screened for all respondents with a depressive feeling, the other researchers used depression diagnostic tools. This method of assessment was used in order to identify all persons with a depressive feeling who are a high risk group for developing depression. Also, because of the overlap of some symptoms in SCD and depression, additional skills may be necessary to accurately make a diagnosis of depression in SCD. A lower prevalence of 22% was reported by John-Olabode et al. [20] in Ogun State in 2015. The observed difference between this present study and that of John-Olabode et al. [20] might be because of the retrospective design of their study which might be compromised due to insufficient information and missing records.

Sixty-one percent of the subjects in this present study avoided the healthcare system compared with 5.0% in the control group. This compares favourably to the findings of other researchers who found that the majority of children and adults with SCA often have poor health care provider communication [21] and avoided the health care system as much as possible [16].

Social withdrawal was observed in 19.5% of subjects in this present study compared to 4% in the control group. The findings in this study are similar to the observations of Morgan and Jackson [22] who found that SCA adolescents had more social withdrawal than their healthy peers for fear of stigmatisation. The subjects in this present study admitted to not talking about themselves much and avoiding social situations due to their disease for fear of stigmatisation. In another study, more than half of the respondents (60%) agreed that they were frequently absent from school because of issues related to SCA and hence had sub-optimal academic performance [23]. Forty percent of respondents in a study in India admitted that recurrent pain interfered significantly with their ability to attend school regularly [12].

Table 1. Age and gender distribution of study subjects and controls

Variables	Subjects n=200 n (%)	Controls n=200 n (%)	Total N=400 n (%)	x^2	p-value
Age (years)*					
10 - 13 years	86 (43.0)	86 (43.0)	172 (43.0)	0.00	1.000
14 - 16 years	85 (42.5)	85 (42.5)	170 (42.5)		
17 - 18 years	29 (14.5)	29 (14.5)	58 (14.5)		
Gender					
Male	97 (48.5)	97 (48.5)	194 (48.5)	0.00	0.999
Female	103 (51.5)	103 (51.5)	206 (51.5)		

**Early adolescence (10-13 years), Mid-adolescence (14-16 years), Late adolescence (17-18 years) [18]*

Table 2. Educational status and family social class of study subjects and controls

Variables	Subjects n=200 n (%)	Controls n=200 n (%)	Total N=400 n (%)	x^2	p-value
Educational status					
Primary	54 (27.0)	50 (25.0)	104 (26.0)	0.12	0.730
Secondary	146 (73.0)	150 (75.0)	296 (74.0)		
Social class*					
High	98 (49.0)	98 (49.0)	196 (49.0)	0.00	1.000
Middle	70 (35.0)	70 (35.0)	140 (35.0)		
Low	32 (16.0)	32 (16.0)	64 (16.0)		

**Social class – High (I-II), Middle (III), Low (IV-V)*

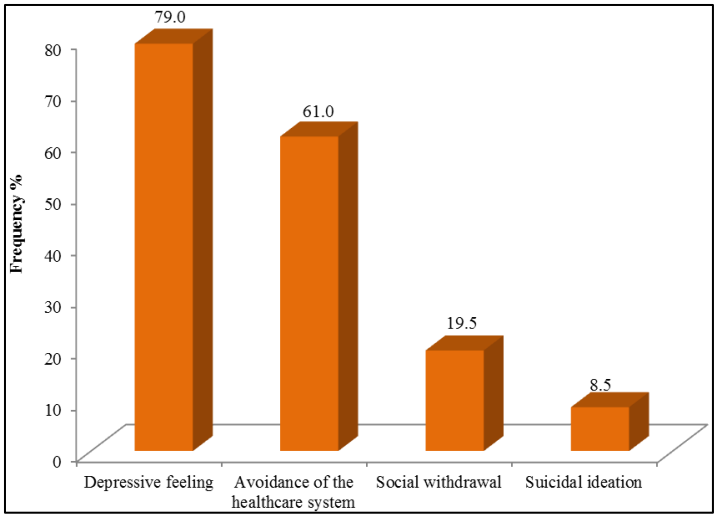

Fig. 1. Psychosocial effects of sickle cell anaemia on the study subjects and controls

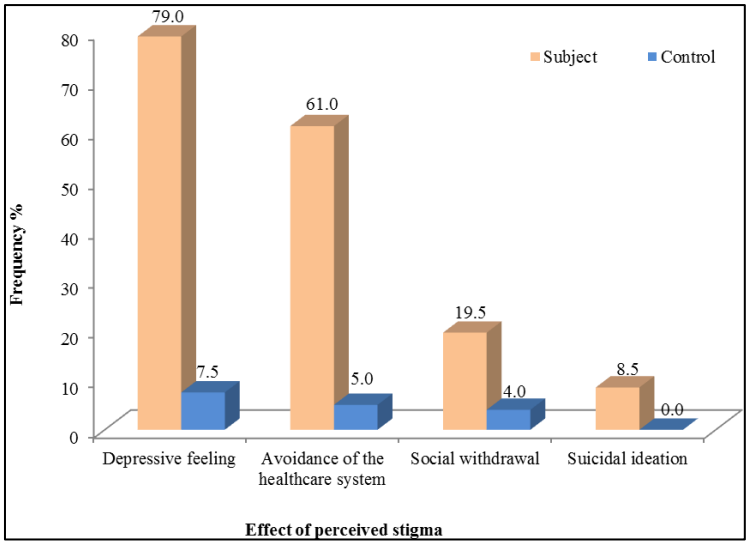

Fig. 2. Psychosocial complications among study subjects and controls

Suicidal ideation was found in 8.5% of subjects in this present study compared to 0% in the control group. This is similar to the reports of a study [20] done in Ogun State, Nigeria which observed a prevalence of 8%. A State Health Resource Centre study in India [12] and Edward et al. [14] in the USA reported higher prevalences of 13.6% and 29% respectively. The mean age of

respondents in the Indian study [12] was 26.86 years while that in the USA study [14] was 30.64 years. These older ages compared to the mean age of 13.79 ± 2.45 years of respondents in this present study might account for the observed differences.

The management of psychosocial problems in SCA bothers on three major pillars: psycho-education, cognitive behavioural therapy and acceptance and commitment therapy. The focus of psychoeducation is enhancing patients' self-esteem and self-efficacy skills through social support and assertion skills training [24]. It improves their knowledge and understanding of the disease while at the same time providing psychological support. Cognitive behaviour therapy and acceptance and commitment therapy work by modifying maladaptive or dysfunctional behaviours. These therapies focus on patients' cognition (thoughts, believes, attitudes), emotions (fear of their disease), behaviours (activity avoidance because of their disease) and the impact of stigma on psychological functioning [24].

5. CONCLUSION

Psychosocial issues constitute a significant problem in adolescents with sickle cell anaemia unlike what is observed in non-SCA adolescents. Regular psychosocial assessment is recommended for every SCA patient on follow up in the Haematology Clinic. Early detection and prompt psychological interventions are key to improving the quality of life in affected persons.

CONSENT

Fully informed Consent was obtained from the parents/guardian of the study participants and participants who were 18 years of age. Assent was obtained from participants aged 10 to 17 years.

ETHICAL APPROVAL

The Research and Ethics Committee of the UPTH gave ethical clearance for this research.

COMPETING INTERESTS

Author has declared that no competing interests exist.

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