Original Article

The impact of sickle cell anemia on the quality of life of sicklers at school age

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Abstract

Background: Sickle cell anemia (SCA) is prevalent in Sudan in general, and in particular in the western part of the country among Misseria tribe. School absence, depressive symptoms, embarrassment, social disturbances, and emotional disturbance present negative impact for sicklers. Therefore, an urgent call for improving the quality of life of sicklers is needed. **Objectives:** To examine the impact of SCA on the quality of life of school-age children affected by the disease from the perspective of three dimensions: psychological, social, and schooling. **Materials and Methods:** This is a prospective, cross-sectional, observational study carried out over 2 weeks' period in April 2011 in Western Sudan, Gineana District. This study included 107 patients within the age group of 7–15 years with confirmed diagnosis of SCA in a steady state. A sickler with SCA who had hemoglobin genotype "SS" on hemoglobin electrophoresis without crises over the past 4 weeks was considered to be in steady state. Questionnaires designed by expert covering social and psychological aspects of the disease were filled by the authors. **Results:** Of 107 patients with confirmed diagnosis of SCA in steady state, 54.2% of them were male. About 17.8%, 29.6%, 23.4%, 48.6%, 16.8%, and 45.8% of the patients suffered from school absence, teasing, embarrassment due to bedwetting, embarrassment due to jaundice, failure to contribute to school activities such as sport, and depressive symptoms, respectively. Around 8.4% of the patients repeated classes. Divorce and anxiety among sicklers' families were found in 6.5% and 8.4%, respectively. Twenty-one (19.6%) families had less interest in social activities in the community. **Conclusion:** Sickle cell disease has many social and psychological problems which need to be addressed. Enuresis, depressive symptoms, school absentees, and deterioration in school performance were the common problems encountered.

Keywords: Absence, anxiety, depression, school, sicklers

Introduction

Sickle cell anemia, which is an inherited condition in an autosomal recessive pattern, is scattered in many parts of the world like Italy, Greece, and Central India, and in some African countries like Sudan.[1,2] Mortality was estimated to raise from 113,000 in 1990 to 176,000 in 2013.[3] More than 75% of the cases are found in Africa, and the World Health Organization estimated 150,000 new cases yearly in Nigeria for instance.[4] Sickle cell anemia (SCA) is prevalent in Sudan in general and in the western part of the country in particular. The prevalence among Misseria tribe in Darfur was estimated to be 30.4%, whereas it was 18% among Misseria Humur of Kurdfan in central Sudan, and the end estimate of one sickler among each 123 children among Misseria and Misseria Humr.[4-6] In Khartoum, the capital of Sudan, where patients reported to Khartoum Teaching Hospital, 5.1% and 0.8% of children were HbAS and HbSS, respectively.[1,4,7] School absence due to the illness and hospital admission can affect the school performance as noted by many authors.[8-10] However, effects on academic performance as noted by Ostia *et al.* (2013) might be developed later as accumulative effect of reflection on socioeconomic status.[11] Presence of patients with SCA will lead to stress, emotional, and social disturbances among families.[12] In general, negative perception was reported from community toward sicklers regarding attitude,

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health problems, educations, and psychological issues.[13] The complications of sickle cell disease (SCD), whether physical, psychological, school achievements, or emotional, were well documented.[14] On considering the quality of life of sicklers, one should never ignore social, emotional, and psychological aspects of the disease.[15] Ilorin University in Nigeria found that social impairment, restriction in physical and social activities, decreased achievement, and feeling depression were common among sicklers.[16]

Objectives

The objective of this study was to examine the impact of SCA on the quality of life of school-age children affected by the disease from the perspective of three dimensions: psychological, social, and schooling.

Materials and Methods

This was a cross-sectional, observational study done over 2 weeks' period in April 2011 in Gineana general hospital, Gineana town, Western Sudan. SCA is known to be prevalent in that area. Gineana general hospital was the only hospital in the town providing medical services in the main specialties including general surgery, medicine, obstetrics and gynecology, and pediatrics and some other minor specialties. During those 2 weeks, there was a medical mission conducted by a group of doctors from different specialties who volunteered to see all patients presented to them. The mission was coordinated with the hospital and announced many weeks before. Ethical clearance was obtained from the research ethics committee of the hospital. Consent was obtained from parents of every patient who participated in the study. Inclusion criteria were age 7–15 years and SCA in a steady state. A steady state was defined as a sickler who had hemoglobin genotype "SS" on hemoglobin electrophoresis without crises over the past 4 weeks.[17] Exclusion criteria included patients with crises or chronic illness such as cerebral palsy, chronic heart disease, renal disease, metabolic disease, or any other disease leading to disability. A structured questionnaire was designed by subject experts including two of the authors. Items of the questionnaire included demographic data, socioeconomic status, and absenteeism from school and perception of patients and their community to their illness. One of the authors was the main interviewer. A pilot study was conducted with 25 patients to check the clarity of the questionnaire. Modified Kuppuswamy's Socioeconomic Scale was used to estimate the socioeconomic status.[18] Recurrent pain and hospital admission beside the absence from school were considered depressive symptoms.[19] For assessment of anxiety and depression, a validated Hospital Anxiety and Depression Scale was used.[20-23] Descriptive statistics was used to calculate the prevalence.

Results

This study enrolled 107 patients with confirmed diagnosis of SCA in steady state; 54.2% of them were male and 45.8% female [Table 1]. About 31 (29%) patients suffered from teasing by their teachers, classmates, and community at large; 25 (23.4%) patients experienced embarrassment from community due to their bedwetting; 52 (48.6%) patients suffered from embarrassment due to jaundice; divorce among sicklers' families was found to be 6.5%; 21 (19.6%) families had less interest in social activities in the community [Table 2]. About 49 (45.8%) and 31 (29%) patients suffered from depressive symptoms and depressive alone, respectively; anxiety was reported in 8.4% [Table 3]. The average school absence was estimated to be 17.8% of the expected attendance. Finally, 9 (8.4%) patients needed to repeat classes; 16.8% patients failed to contribute to school sport activity [Table 4].

Discussion

Of 107 patients with confirmed diagnosis of SCA in steady state, 54.2% of them were male. About 17.8%, 29.6%, 23.4%, 48.6%, 16.8%, 45.8%, and 31 (29%) of the patients suffered from school absence, teasing, embarrassment due to bedwetting, embarrassment due to jaundice, failure to contribute in school activities such as sport, and depressive symptoms and depressive depression only, respectively. Divorce and anxiety among sicklers' families were found in 6.5% and 8.4%, respectively. Twenty-one (19.6%) families had less interest in social activities in the community.

Table 1: Gender distribution

Gender	No. (%)
Males	58 (54.2)
Females	49 (45.8)
Total	107 (100)

Table 2: Social problems among sicklers

Problems	No. (%)
Divorce	7 (6.5)
No interest in social activity	21 (19.6)
Teasing	31 (29)
Embarrassment about bedwetting	25 (23.4)
Embarrassment about jaundice	52 (48.6)

Table 3: Psychological disturbances among sicklers

Psychological disturbances	Frequency (%)
Anxiety	9 (8.4)
Depressive symptoms	49 (45.8)
Depression only	31 (29%)
Total	89 (83.2%)

Table 4: Problems of schooling among sicklers

Parameters related to schooling	Frequency (%)
Failure to participate in extracurricular activities (sports)	18 (16.8%)
School absence	19 (17.8%)
No. of repeaters	9 (9 (8.4%)

This is the first study to investigate social impact of SCD in Sudan. School absence presents as one of the major stresses to the children and their families, which was estimated to be 17.8% from the normal expected attendance. Studies done among Nigerian sicklers considered it as a major cause of school absenteeism.[23] Studies done among Nigerian sicklers showed that 15.85% had school absence;[11] however, both our findings and the Nigerian study proved higher rate than USA study.[9,24,25] The social, medical and psychological supports in USA definitely better than our set up. In the United Kingdom, school absence is estimated to be 8.4% of the expected school attendance, which is twice the absence days from other illnesses (according to the Department for Children, Schools and Families [DCSF], 2008).[26] Usually, this absence might be explained due to repeated hospital admission due to different types of crises.[1,27] Crises in general and pain in particular can lead to severe morbidity and death if not recognized and handled meticulously[28,29] In this study, school absence, frequent abdominal pain, and frequent hospitalizations were encountered in 47% of the patients (depressive symptoms). These agree with some studies which report depressive symptoms among sickler.[3,11,26] Consistent with the literature, a considerable number of the patients in this study had feelings of depression. Ohaeri *et al.* reported that 55% of their sicklers were depressive[14,30] among Nigerian children with SCD. Our finding for depressive illness was less than Nigerian study due to difference in defining depression. Depressive illness will be understood in view of low cognitive process as documented by some authors.[31] The impact of socioeconomic status has been observed in this study. Nine (8.4%) patients were from low socioeconomic class. Previous study also demonstrated low academic performance among patients with low socioeconomic status.[11,32] The presence of sicklers in the family associated with some disturbance among family members like divorce, anxiety, emotional disturbances, and less commitment in social activities among the community. Burlew *et al.* (1989) demonstrated psychological and social disturbances among sicklers and their family.[12] Of course repeated hospital visits due to crises can create stress among all family members. School problems such as teasing regarding their jaundice, failure to participate in school activities, and embarrassment due their enuresis were reported in this study. Similar results were reported by Kofi *et al.* (2010).[13] Adequate health education for patients, their families, and the community at large will minimize the social, financial, psychological, and even clinical trauma.[33] The low cognitive in sicklers showed adverse effect on the socioeconomically status of patients with SCA.[34]

Conclusion

SCD has many social and psychological problems that need to be addressed. For example, enuresis, depressive symptoms, school absentees, and deterioration in school performance.

Recommendation

Social supports are highly suggested for chronic illness in general and sicklers in particular. Also, regular psychological check up is recommended for sicklers and their families. Social workers should be advised to revise families' circumstances financially and socially.

Limitation

The use of questions that were only answered by yes or no might limit full information to express the exact problems faced by the patients or their families. The other limitations include difficulty in estimating exactly the magnitude of depressive symptoms, anxiety, emotional, and social disturbances among sicklers and their families.

Strength

The strength of this study is it addresses very important part in managing sicklers and their families.

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Conflicts of interest

There are no conflicts of interest.

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