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Research Article

Knowledge and Experience of Adolescents with Sickle Cell Disease in the Hospitalier Universitaire Mere-Enfant Foundation Jeanne Ebori in Libreville

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ABSTRACT

Introduction: Sickle cell disease remains a major public health problem in Sub-Saharan countries. It disrupts the social life of children and adults with the disease. The aim was to assess adolescents level of knowledge and report on their experiences of sickle cell disease.

Methods: Semi-qualitative, descriptive study over a 2-month period. We included adolescents with sickle cell disease who had been informed of their status with informed parental consent. The statistical analysis was carried by utilizing Epi Info 7.2.2.

Results: We collected data from 40 adolescents with sickle cell disease. The sex ratio was 0.7 with 56.8% girls. The mean age was 13.7 ± 2.5 years. The mean age of discovery was 3 ± 3.14 years, with a median age of diagnosis of 7 years. They were attending school 91.9% and 37.8% were behind in their schooling. Knowledge of sickle cell disease was effective in 78.4% of cases and 51.2% had very good knowledge of preventive measures. The disease was accepted in 32.4% of cases and 29.7% were afraid. Hygiene measures and repeated hospitalisations were resented in 24.3% of cases. In 40.5% of cases, they felt different from the other children and 13.5% had a conflictual relationship with their siblings. For 13.5%, the 2 most significant events were the death of a sickle cell brother and the occurrence of serious complications. The occurrence of new attacks was feared by 49.5% of them and 29.7% were afraid of dying.

Conclusion: Sickle cell disease has an impact on the lives of patients and their families. Control measures involving awareness-raising and psychological support are needed to reduce the morbidity and mortality associated with this disease.

Keywords: Sickle cell disease; Adolescent; Pediatrics; Chronic illnesses

INTRODUCTION

Sickle Cell Disease (SCD) is one of the most widespread genetic diseases in the World Health Organization (WHO) African region. In almost 40 countries, the prevalence rate of sickle cell disease is estimated to be at least 2% [1]. It remains a major public health problem in Sub-Saharan countries. Because of its genetic nature, it affects family life, bloodlines and offspring. The unpredictable nature of its symptoms (painful attacks, anaemia, complicated forms) disrupts the social life of the child or adult suffering from the disease. For this reason, the WHO has stressed the need to set up support groups for people living with sickle cell disease in order to strengthen management strategies in the African region [2]. Few African studies have been carried out on the psychological profile of children and adolescents living with sickle cell disease. With a view to improving management, we conducted this study to assess adolescent's level of knowledge and experience of the disease.

MATERIALS AND METHODS

This was a semi-qualitative descriptive study. The study took place in Libreville between 1st February and 1st April 2023. The study took place in the general paediatrics department of the Centre Hospitalier Universitaire Mere-Enfant Foundation Jeanne Ebori (CHUME-FJE).

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This is a level 3 hospital dedicated to maternal and child health, in operation since 2019. The study population consisted of adolescents with sickle cell disease who were informed of their status and for whom we obtained informed consent from their parents. The variables studied were essentially the socio-demographic data of the study population, their habits and lifestyle, the natural history of sickle cell disease, their theoretical knowledge, their experiences and their relationships with their family and friends. Data were collected at the patient's bed and then recorded on a pre-established standardized data collection form. They were entered into Epi info software version 7.2.2. The results of quantitative variables were presented as means with their standard deviation. Numbers and percentages were used to express the qualitative characteristic. The data's confidentiality and anonymity were ensured.

RESULTS

During the study period, we enrolled 40 adolescents with sickle cell disease. The mean age was 13.7 years ± 2.5 years, with extremes of 10 years and 18 years. The age range 10 years to 15 years accounted for 60.0% of cases. The sex ratio was 0.7, with females predominating (n=23). Adolescents with sickle cell disease attended school in 90.0% of cases. The level of education was secondary (60.0%) and primary (27.5%). Adolescents with sickle cell disease were behind in school in 37.5% of cases. Adolescents with sickle cell disease lived in urban areas (62.5%) and in two-parent families in 50.0% of cases. Other children with sickle cell disease were found in 29.7% of siblings. The age of onset of the disease was 3 years ± 3.1 years, with extremes of 7 months and 14 years. In 22.5% of cases, sickle cell disease was discovered during a systematic work-up in children of parents carrying the sickle cell gene and in 20.0% of cases during a hand-foot syndrome. The age at diagnosis was 7.7 years ± 1.6 years, with extremes of 4 years and 14 years. In 70% of cases, the announcement of sickle cell status was made by the parents and in 16.2% the initiative came from the sickle cell patient himself. They were followed up in 89.2% of cases. As regards knowledge of sickle cell disease, 70.0% of them had heard of it before. The definition of sickle cell disease was known (77.5%). Half the adolescents with sickle cell disease were aware of measures to prevent attacks (52.5%) and the complications of the disease (60.0%). As regards the experiences of adolescents with sickle cell disease, fear and sadness predominated when they were told they had sickle cell disease (55.0%). Hygiene measures (37.5%) and repeated hospitalisations (27.5%) were what bothered adolescents with sickle cell disease the most. In 87.5% of cases, they had a good relationship with their siblings. They felt different from other children in 42.5% of cases. They feared another attack (47.5%) and were afraid of dying (27.0%). The average age of awareness of the disease was 10 years ± 1.6 years, with extremes of 6 years and 15 years. The main factors leading to awareness were recurrent attacks (47.5%), complications of sickle cell disease (15.0%), being treated differently by others (15.0%) and the death of a sibling with sickle cell disease (12.5%) as shown in (Table 1).

Table 1: Socio-economic data.

Parameters	Work force	Percentage (%)
Sex		
Women	23	57, 5
Male	17	42, 5
Age (an)		
(10ans-15ans)	24	60, 0
(15ans-19ans)	16	40, 0
Enrolled		
Yes	36	90, 0
No	4	10, 0
Level of study		
Primary	11	27, 5
Secondary	24	60, 0
University	5	12, 5

DISCUSSION

Age

The mean age of discovery of sickle cell disease was 3 years. This result is comparable to those reported in the literature. The mean age of diagnosis was 2 years in the Democratic Republic of Congo and Congo [2,3]. This result is justified by the fact that this age bracket corresponds to the age of onset of the first symptoms. Furthermore, the age at which sickle cell disease status was announced was 7.7 years ± 1.6 years. This age corresponds to primary school age, when the child can understand and store certain information.

School attendance

Adolescents with sickle cell disease attended school in 90.0% of cases and 10.0% of them had to drop out. They were behind in school in 37.8% of cases. This result is comparable to that of Bat-Pitault [4], in the Congo, who reported that 33% of children were behind in their schooling and 8.4% had to drop out. These observations were also made by Fouda [5], in his work carried out in Normandy in 2021. Sickle-cell anaemia is a serious disease with many acute and chronic complications, leading to repeated hospitalisations, severe fatigue and difficulty concentrating. These are often the causes of fairly regular absenteeism from school, which leads to academic failure in these children. The literature reports that in chronic illnesses, absenteeism from school and repeating a year increase the age difference with other pupils and therefore the feeling of being different, which can lead to a drop in self-esteem and anxiety [4-6]. Not being able to go to school puts these young people at a disadvantage compared with their peers. The physical suffering created by this disease will be responsible for psychological suffering which may lead sickle cell sufferers to lose interest in their studies. Bat-Pitault's study in the Congo reported that the subject's quality of life was good when they had normal schooling and puberty.

Knowledge of sickle cell disease

In our study, half the adolescents with sickle cell disease had knowledge of the disease (52.5%) and its complications (60.0%). This result is comparable to that found in the Democratic Republic of Congo (55.8%) [7,8]. These results show that the level of knowledge about sickle cell disease is average and suggest that it is imperative to step up measures to raise awareness of this serious disease in order to improve its management. Indeed, understanding sickle cell disease requires accurate knowledge of its origin, symptoms and course, which is often associated with early death, especially in sub-Saharan Africa as shown in (Table 2).

Table 2: Knowledge of adolescents with sickle cell disease.

Knowledge about sickle cell disease	Work force	Percentage (%)
Have you heard of sickle cell disease		
Yes	28	70, 0
No	12	30, 0

Definition of sickle cell disease		
Good knowledge	31	77, 5
Don't know	9	22, 5
Preventive measure		
Good knowledge	21	52, 5
Fair	12	30, 0
No knowledge	7	17, 5
Complications of sickle cell disease		
Good knowledge	24	60, 0
Fiar	10	25, 0
No knowledge	6	15, 0
Knowledge of the duration of the illness		
Good knowledge	34	85, 0
No knowledge	6	15, 0

Feelings when the illness was announced

Fear was the dominant feeling when the disease was announced. This result is similar to that found by Luboya [9], in the Democratic Republic of the Congo (DRC) and Lambotte [8], in Belgium. This is justified by the fact that the adolescents had become aware that sickle cell disease is a serious, incurable and potentially fatal disease.

Feelings in relation to other children

Adolescents with sickle cell disease felt different from other children in 42.5% of cases. This result is similar to that of Mpandzou [2], in Congo (48.2%) as shown in (Table 3). This resentment is justified by the fact that, in our context, children with sickle cell anaemia are often victims of stigmatisation by both society and their families. The morphological aspect is one of the stigmatising factors that are at the root of the deterioration in quality of life. For Lambotte [8], it's the feeling of being different from their peers. They are treated as fragile children and often singled out. They are also subject to a number of prohibitions and rules (little physical activity, certain games are forbidden, they must drink plenty of fluids, etc.). The limits imposed by the disease assign the patient to a particular position. Some may derive secondary benefits, while others suffer frustration as a result. At school, classmates can be destabilised. They are afraid to ask questions about the disease and have preconceived ideas about their classmates [10-13]. That's why it's important to give students brief, general information. This will give them a better understanding of their classmates' condition.

Table 3: Adolescents with sickle cell disease and their experiences of the disease.

Parameters	Work force	Percentage (%)
Announcement of sickle cell disease status		
By parents	28	70, 0
By doctors	7	17, 5
Patient initiative	5	12, 5
Feelings at the time of announcement		
Fear	13	32, 5
Acceptance of illness	12	30, 0
Sadness	9	22, 5
Felling of injustice	6	15, 0
What's disturbing about sickle cell disease		
Hygiene measure	15	37, 5
Recurrent hospitalisation	11	27, 5
Daily treatment	8	20, 0
Disease-related stereotypes	6	15, 0

Relationship with siblings

The relationship between adolescents with sickle cell disease and their siblings was good in 87.5% of cases and conflictual in 12.5% of cases. The literature has also made this remark. In this study, Lambottea [8], found that adolescents with sickle cell disease had a good relationship with their siblings. Nsangou [10], in Cameroon reported that adolescents with sickle cell disease were jealous of their brothers and were treated differently. In the majority of cases, sickle cell anaemia has led to the parentalisation of the siblings of the affected child in relation to the monitoring and management of the latter. On the other hand, this conflictual relationship results from the feeling of jealousy and injustice created by the disease. The sick teenager is jealous of their brothers who are in good health and finds this situation unfair. The latter are jealous of the attention they receive from their parents.

Fear of the disease

Adolescents with sickle cell disease were afraid of dying in 27.0% of cases. In this study conducted in Cameroon, Nsangou [10], reported that adolescents with sickle cell disease had no prospects for the future in 30.0% of cases as shown in (Table 4). This result can be explained by the fact that the physical suffering caused by sickle cell disease has an impact on the psyche. This psychological suffering prevents adolescents with sickle cell anaemia from projecting themselves into the future. This pain generates anguish, fear and intense emotions, leading to a search for meaning in order to escape despair. Several studies have highlighted the relationship between depression and the number of painful attacks, the number of blood transfusions and the number of hospitalisations [2,14-16]. These feelings may be linked to the perception of the chronic nature of the disease. The cognitive integration of the idea of experiencing these attacks for the rest of their lives, with no real respite and eventually dying from them, prevents them from imagining their future and they end up mourning the prospect of recovery.

Table 4: Experiences of adolescents with sickle cell disease: Relationships with siblings and family and friends.

Parameters	Work force	Percentage (%)
Relationship with siblings		
Good relationship	35	87, 5
Conflict	5	12, 5
How do you feel about other children?		
Normal	23	57, 5
Differents	17	42, 5
Fears about disease		

New crises	19	47, 5
Death	11	27, 0
Repeated hospitalisation	5	12, 5
Occurrence of complications	5	12, 5

CONCLUSION

Sickle cell disease is a legitimate public health concern. Adolescents with sickle cell disease have a fair level of knowledge about the disease. Fear and low self-esteem remain the predominant feelings. Psychosocial care is vital if sickle cell disease is to be better managed in children. Much remains to be done to reduce the morbidity and mortality associated with this disease. Collaborative efforts among healthcare professionals, policymakers, advocacy groups and affected communities are needed to implement comprehensive strategies that address both the medical and psychosocial dimensions of the disease. By prioritizing holistic care and support, we can strive towards better outcomes and improved quality of life for individuals living with SCD.

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