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Psychological Experience of Mothers of Children with Sickle Cell Disease Followed at the Pediatric Department of Bouaké University Teaching Hospital

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Abstract

Introduction: Sickle cell disease has physical and emotional repercussions on the child and his family. The aim of this study was to describe the psychosocial experiences of mothers of children with sickle cell disease in order to improve the overall care of the child. **Methods**: This was a descriptive cross-sectional study carried out in the pediatrics department of Bouaké University Teaching Hospital from June to September 2023. It focused on mothers of major sickle-cell-affected children followed up in the pediatrics department of the Bouaké University Teaching Hospital. The variables studied were sociodemographic, psychological, social and economic. **Results**: Of the 40 mothers surveyed, 15% were not in school and 32.5% were unemployed. For them, sickle cell disease was of natural (genetic) origin in 90% and supernatural in 10%. They stated that the child had an average age of 36 months (extremes 7 and 108 months) when the disease was discovered. And 52% of them were satisfied with the way the disease was clearly and completely announced. Following the announcement, the questioned mothers said they had felt shock (35%), sadness (31.7%), guilt (23.3%) and discouragement (10%). Anxiety and depression were experienced by 77.5% and 22.5% respectively. In 60% of cases, they stated that the disease was incurable, and the outcome was fatal in 2.5% of cases. The child's illness was a source of problems in the home in 25% of cases, represented by arguments in 92% and divorce in 8%. In 97.5% of cases, the mother told her family and friends about the child's illness. In 90% of cases, the mother and child benefited from psychological support from family and friends. **Conclusion**: Sickle cell disease is a serious illness with a

psychological and social impact on mothers. We recommend psychological support for mothers from the moment of diagnosis and throughout follow-up.

Keywords

Psychosocial Experience, Sickle Cell Disease, Côte d'Ivoire

1. Introduction

Sickle cell anaemia is the world's most common haemoglobinopathy. It affects 3% to 3.6% of the world's population [1]. In 2021, more than 300 million people were carriers of the sickle cell trait, and around 6.4 million people were living with the disease. Every year, 300,000 children are born with the disease, 2/3 of them in sub-Saharan Africa [2]. In Africa, the frequency of carriers of the sickle cell gene varies from one region to another, but is high overall, reaching prevalences of 40% in certain populations [3]. In Côte d'Ivoire, recent epidemiological data have indicated a prevalence of 14% in the general population [4]. While this figure is significant from an epidemiological point of view, little is known about the clinical manifestations of the disease. In addition to the acute manifestations, dominated by painful vaso-occlusive attacks and anaemia, which are the cause of frequent hospitalisation of children, there are also chronic degenerative complications at organ level, delayed height and weight gain and delayed puberty [5] [6] [7]. In most countries with limited resources, such as Côte d'Ivoire, where sickle cell disease is a major public health concern, the basic resources for its management are inadequate, systematic screening for the disease at birth is not carried out, and diagnosis is generally made late at the complications stage [8] [9]. Follow-up of children is often irregular due to a number of more or less interrelated factors, including the absence of specialised care centres, inadequate resources (material and human), and parental poverty. Sickle cell disease has a negative impact on the psychological experience of the patient, the parents and the family. A child with sickle cell anaemia lives in pain, some of the most intense that can be described. However, in addition to this pain, there is another, more diffuse, psychological pain which affects the whole of the child's life, as well as those around him [10]. The announcement of the diagnosis of sickle cell disease is an emotional shock for the parents because it is often associated with an early death, a stigmatising disease because of the way it is transmitted and the many handicaps it causes. In the African cultural context, the mother is the parent who is most narcissistically wounded by the discovery of sickle cell disease in her child [11] [12]. From then on, the repeated crises of a child with sickle cell anaemia plunge the mother into absolute uncertainty, the threat of annihilation, absurdity and death. The parents' anxiety is often massive, heightened by a feeling of guilt linked to their inability to relieve their child's suffering [12]. The succession of crises and hospital stays eventually has repercussions on married

life, even leading to divorce, and reduces the family's financial resources [13]. In current practice, the sick child is at the centre of nursing staff's preoccupations, and treatment remains almost entirely medical, while the parents' psychological experiences are often overlooked. The aim of this study is to describe the psychosocial experience of mothers of children with sickle cell disease in order to improve the overall management of the child.

2. Methods

This was a prospective cross-sectional study conducted in the pediatrics department of Bouaké University Teaching Hospital (UTH) from June to September 2023. The study population consisted of mothers of the children in the active file of sickle-cell children followed up in the department. All consenting mothers of children with sickle cell anaemia followed in the paediatric department of Bouaké UTH were included in the study. Mothers of children with sickle cell disease who were absent from their child during the survey were not included in the study. Thus, 40 mothers were selected for the study. The study took place over a period of 03 months, from 05 June to 05 September 2023. For each child, only the mother was interviewed. The interviews were conducted face-to-face. Data were collected using a computerised, structured and anonymous questionnaire containing the following study variables: 1) socio-demographic characteristics of the mother-child pair (age at onset of the disease, number of hospitalisations, number of attacks, parents' level of education, social and economic conditions), 2) mothers' psychological experience defined in the following terms according to the National Textual and Lexical Resources Center (NTLRC) [14]:

Anxiety: Intense worry, linked to a situation of expectation, doubt or loneliness, which leads us to foresee misfortune or serious suffering in the face of which we feel powerless.

Depression: A psychosomatic state caused by a disturbance in mood, resulting in the absence of normal alternations between joy and sadness.

Fatigue: Discouragement, loss of desire to continue what has been started.

Sadness: A state of inability to feel joy or show cheerfulness.

Guilt: A more or less anxious and morbid state in which a person feels guilty about something.

Level of study: low = none and primary, good = secondary and above

3) social and economic impact of the disease.

The questionnaire was drawn up by the pediatric medical team at Bouaké UTH, with the support of the hospital's psychiatric doctors. It was then validated by means of a pre-test on a random sample of 10 mothers. Following the results of the pre-test, certain modifications were made to the questionnaire. The final version of the questionnaire was adopted and validated after a revision of the order and wording of the questions. The data were entered and analysed using Excel 2019 software. Quantitative variables were expressed as median, mean and extremes. Qualitative variables were expressed as proportions.

This study was carried out after obtaining authorisation from the Medical and

Scientific Director of Bouaké UTH, under cover of the Head of Paediatrics Departement. Anonymity and confidentiality were respected by assigning an anonymity number to each questionnaire form.

3. Results

3.1. Socio-Demographic Characteristics

Of the 40 children registered, 24 were boys and 16 girls, giving a sex ratio (B/G) of 1.5. The average age of the children was 8 years [extremes 23 months; 180 months] and 78% were over 5 years of age. The disease was discovered incidentally in 62.5% of cases. The mean age at diagnosis was 3 years, and 77.5% of children were diagnosed before the age of 5. The child's electrophoretic profile was haemoglobin SFA2, SS, SC in 42.5%, 27.5% and 25% respectively. The children had health insurance in 40% of cases. The mothers were under 35 in 40% of cases. They had a low level of education in 45% of cases, were housewives in 32.5% and 50% had a monthly income of less than 50,000 XOF. The mothers were married in 22.5% of cases. The child was born of a consanguineous union in 12.5% of cases and they had more than one sickle cell child in 35% of cases. The socio-demographic characteristics of the children and their mothers are presented in Table 1.

3.2. Psychological Experience of Mothers

The announcement was not complete in 47.5% of cases, according to the mother. It was made in the mother's presence in 67.5% of cases, and took place in the doctor's office in 67.5% of cases. Emotional shock (35%), sadness (31.7%) and guilt (23.3%) were the feelings experienced by the mother when the illness was announced. The mother's reaction to the diagnosis was anxiety in 77.5% of cases and depression in 22.5%. For almost two-thirds (60%) of the mothers, the disease was incurable, and 2.5% thought it was fatal.

The psychological experiences of the mothers are presented in Table 2.

Table 1. Distribution of children with sickle cell disease and their mothers according to socio-demographic characteristics.

Variable	Frequency	Percentage
Child		
Gender		
Male	24	60
Female	16	40
Age		
≤5 years	12	30
>5 years	28	70
Age at diagnosis		
≤5 years	31	77.5
>5 years	9	22.5

Continued

Circumstances of discovery		
Fortuitous	25	62.5
Hospitalization	15	37.5
Electrophoretic profile		
HbSS	11	27.5
HbSC	10	25
HbSFA2	17	42.5
HbSAFA2	2	5
Existence of health insurance		
Yes	16	40
No	24	60
Mother		
Age		
≤35 years	16	40
>35 years	24	60
Level of study		
Low	18	45
Good	22	55
Professional activity		
Housewife	13	32.5
Informal sector worker	17	42.5
Civil servant	10	25
Monthly income*		
<50,000 XOF	20	50
50,000 - 100,000 XOF	8	20
>100,000 XOF	12	30
Marital status		
Married	9	22.5
Unmarried	31	77.5
Child born of a consanguineous union		
Yes	5	12.5
No	35	87.5
Number of children with sickle cell disease		
1 child	26	65
>1 child	14	35

*1 XOF = 0.0015 € = 0.0017 $.

Table 2. Breakdown of mothers of children with sickle cell disease by psychological experience.

Variable	Frequency	Percentage
Announcement of the diagnosis		
Complete	21	52.5
Incomplete	19	47.5
Parent in attendance		
Mother only	27	67.5
Both parents	13	32.5
Place of advert		
Isolated	27	67.5
With other patients	13	32.5
Feelings at the time of the announcement		
Shock	21	35
Sadness	19	31.7
Guilt	14	23.3
Discouragement	6	10
Reaction to the announcement		
Anguish	31	77.5
Depression	9	22.5
Vision for the child's future		
Incurable disease	24	60
Hope for a cure	15	37.5
Fatal outcome	1	2.5

3.3. Economic and Social Repercussions of the Disease

The mother used traditional medicine in 65% of cases. In 22.5% of cases, the mother was responsible for paying for the treatment, and 67.5% had stopped work to look after the sick child. The illness had no impact on the child's life in the family. The child's illness was a source of tension in the household in 25% of cases, and these tensions were arguments in 92% of cases and divorce in 8% of cases. In 97.5% of cases, the mother told her family and friends about the child's illness. The mother and child received psychological support from their family and friends in 90% of cases. The economic and social impact of the child's illness on the mothers is shown in Table 3.

4. Discussion

The aim of this descriptive cross-sectional study, carried out over a period of 3 months in the paediatrics department of Bouaké University Teachning Hospital, was to describe the psychological experiences of mothers of children with major

Table 3. Distribution of mothers of children with sickle cell disease according to the economic and social impact of the disease.

Variable	Frequency	Percentage
Economic impact		
Use of traditional medicine		
Yes	26	65
No	14	35
Person responsible for expenses		
Father only	24	60
Mother only	9	22.5
Both parents	7	17.5
Stopping work		
Yes	27	67.5
No	13	32.5
Social repercussions		
• **Impact on the child's life in the family**		
No	40	100
• **Tension in the relationship**		
Yes*	10	25
No	30	75
Sharing information with family and friends		
Yes	39	97.5
No	1	2.5
Psychological support for family and friends		
Yes	36	90
No	4	10

* arguments *11*, *divorce 1*.

sickle cell disease. The study showed that the discovery of major sickle cell disease in a child often alters the mother's psychological and social experience. For the majority of mothers, the announcement of the diagnosis provokes shock, sadness, feelings of guilt, anxiety and depression. This can lead to problems in the relationship, such as financial difficulties, giving up work, arguments and, in some cases, divorce. These results need to be qualified for the following reasons. Not all the mothers of adult children with sickle cell disease were able to take part in the survey because they could not be contacted or were unavailable, which explains the small size of the study sample. Also, given that all the data in the study were declared by the mother, recall and desirability biases likely to affect some of the results may have occurred. Despite the methodological limitations, this study has the merit of being, to our knowledge, the first qualitative

study on sickle cell disease in Côte d'Ivoire. It raises the following points for discussion:

4.1. Socio-Demographic Characteristics

The study revealed that sickle cell disease affects more boys than girls, with a sex ratio (B/G) of 1.5. This result is similar to those of Diagne *et al.* [15] Charuhas *et al.* [16] in India, who found a sex ratio of 1.02 and 1.3 respectively. In contrast, Shongo *et al.* [17] in Congo Democratic Republic and Nacoulma *et al.* [18] in Burkina Faso respectively noted a female predominance with a sex ratio of 0.86 and 0.67. These differences are thought to be related to demographic differences in each country, since transmission of sickle cell disease is not sex-linked [19]. In this study, the mean age at discovery of sickle cell disease was 3 years, with more than three quarters (77.5%) discovered before the age of 5. This result is similar to that of Adoku *et al.* [20] in Nigeria, where almost three quarters of children were diagnosed before the age of 3. This delay in diagnosis could be explained by the fact that almost two-thirds (62.5%) of diagnoses were made by chance. Also, in developing countries, diagnosis is rarely made before the age of 2 and neonatal screening is not carried out systematically [17]. The introduction of a routine screening programme, which could be prenatal, neonatal or linked to child protection services such as vaccination, would considerably reduce the number of children whose diagnosis is delayed. In this study the electrophoretic profiles were predominantly HbSFA2 at 42.5%, HbSS at 27.5% and HbSC at 25%. This result differs from that of *Brown et al.* [21] in Nigeria who noted HbSS (92.1%) and HbSC (7.9%) This difference could be explained by a large regional disparity in sickle cell phenotypes [22]. This study shows that 32.5% of mothers are housewives and 50% have a low income of less than 50,000 XOF per month. Shongo *et al.* [17] in their study noted that 70% of mothers had a low socio-economic level. This result could be explained by the high rate of mothers with a low level of education (45%) in this study, especially since professional activity most often results from the level of schooling [23]. Also, according to UNICEF, each year spent at school enables a girl to increase her future income by 10% to 20%. Furthermore, investing so that girls can complete higher education could help to increase their lifetime income by up to 68% of annual Gross Domestic Product [24].

In this study, consanguinity between father and mother was 12.5%. Some studies have noted a higher rate of consanguinity ranging from 44% to 50.25% [25] [26]. These high rates of consanguineous marriages could be explained by tribal culture. Indeed, studies have shown that consanguineous marriages are favoured to eliminate social risk and ensure the safety of women and children by strengthening family ties and preserving wealth [27]. However, this practice increases the probability of homozygosity and therefore the incidence of recessive genetic diseases in the population [28]. Community awareness campaigns are needed to curb this scourge.

4.2. The Mother's Psychological and Social Experience

In this study, for 67.5% of parents, the announcement was made in the doctor's office, in good conditions with no interruptions. More than half (52.5%) of the parents felt that the announcement was clear and complete. However, for some mothers, the announcement led to psychological disturbances such as shock (35%), sadness (31.7%) and guilt (23.33%). In Congo, Luboya *et al.* [29] reported that sadness, worry and anxiety were the reactions and feelings most frequently experienced by mothers. This result could be explained by the fact that mothers did not have sufficient information about the disease. More than half (60%) said that it was an incurable disease, and for 2.5%, the fatal outcome was inevitable. Thus, the announcement of a chronic disease such as sickle cell anaemia is experienced as a catastrophe, generating terrible anxiety and moral suffering for the parent. This moment, defined as a cataclysm in the eyes of the parents, provokes several changes in their lives and involves a process of adaptation [30]. Generally speaking, it is thought that the emotional impact caused by the revelation of a diagnosis of serious illness can be divided into three main phases: the initial collapse, the development of defence mechanisms and finally acceptance of the diagnosis. These stages appear to parallel the experience of a bereavement process [31].

In this study, 97% of the mothers said that they had told those around them about their child's illness. The disease had no impact on the child's social life, as none of them felt different from the other children and had not suffered discrimination, rejection or mockery. However, the impact of sickle cell anaemia on social life is terrible for some couples, where conflicts in the home have been noted, even leading to divorce. This finding was highlighted in the study by Luboya *et al.* [29] where the majority of mothers reported that their child's illness had changed the family atmosphere. The illness remained hidden from the family circle, and the parents managed the situation alone during or outside crises, so that information was not disseminated within the community. Parents in general, and mothers in particular, believe that the discovery of the disease could put an end to their marriage if family members were aware of the situation. In sub-Saharan societies, sickle cell anaemia is seen as a request from the ancestors to the patient's family to make amends for a transgression of an ancestral norm. Generally, the mother is held responsible for this transgression. Divorce is then seen as the solution to put an end to the curse [11].

4.3. Economic and Social Impact

In this study, care was provided solely by the parents in 100% of cases, and in 22.5% of cases the mother provided all the care alone. Financial difficulties were omnipresent and reported by all the mothers interviewed, as the majority of mothers had low incomes. Sickle cell disease has a major economic impact on families, as treatment for sickle cell disease is expensive. According to Ouedraogo *et al.* [32] the average cost of outpatient treatment is 41,838.82 XOF and inpa-

tient treatment 106,688.70 XOF. Because of the lack of a social security system (60%), this treatment is very expensive for parents, most of whom have a low socio-economic level and more than one sickle cell child (35%). In addition, access to specialist sickle cell treatment centres is a major obstacle for most children and their families, as there are very few sickle cell treatment units in the country. Poverty, recurrent attacks and the feeling that Western medicine is powerless can lead parents to turn to traditional medicine because of its accessibility and lower cost. In this study, 65% of mothers used traditional medicine. Socio-cultural considerations make a major contribution to this [33].

5. Conclusion

Sickle-cell anaemia is a serious disease which has a psychological, social and financial impact on parents in general and mothers in particular. The announcement of the diagnosis is a key moment on which the success of treatment and the relationship between parents and carers may depend. Their experience is characterised by psychological disorders, triggered by the announcement and persisting in everyday life. The specific characteristics of our society affect the way we react and adapt to illness. Psychological support is essential from the moment the diagnosis is made and throughout the follow-up.

Authors' Contributions

All authors participated intellectually in the preparation and revision of the manuscript prior to its submission.

Conflicts of Interest

The authors declare no conflicts of interest regarding the publication of this paper.

References

[1] Modell, B. and Darlinson, M. (2008) Global Epidemiology of Haemoglobin Disorders and Derived Service Indicators. *Bulletin of the World Health Organization*, **86**, 480-487. https://doi.org/10.2471/BLT.06.036673

[2] World Health Organization (2006) Sickle Cell Anaemia. Agenda Item 11.4. 59th World Health Assembly, WHA59.20.

[3] Okwi, A.L., Byarugaba, W., Ndugwa, C.M., Parkes, A., Ocaido, M. and Tumwine, J.K. (2010) An Up-Date on the Prevalence of Sickle Cell Trait in Eastern and Western Uganda. *BMC Hematology*, **10**, Article No. 5. https://doi.org/10.1186/1471-2326-10-5

[4] Sangaré, A., Koffi, K.G., Allangba, O., Tolo, A., Coulibaly, F.H., Sanogo, I.V., *et al.* (1997) Etude comparative du Ketoprofène et de la Buprenorphine dans le traitement des crises douloureuses drépanocytaires. *Medecine d'Afrique Noire*, **4**, 138-143.

[5] Ohaeri, J.U. and Shokunbi, W.A. (2001) Attitudes and Beliefs of Relatives of Patients with Sickle Cell Disease. *East African Medical Journal*, **78**, 174-179. https://doi.org/10.4314/eamj.v78i4.9058

[6] Tunde-Anyinmode, M.F. (2007) Psychosocial Impact of Sickle Cell Disease on Mothers of Affected Children Seen at University of Ilorin Teaching Hospital, Ilorin, Nigeria. *East African Medical Journal*, **84**, 410-419. https://doi.org/10.4314/eamj.v84i9.9550

[7] Palermo, T.M., Riley, C.A. and Mitchell, B.A. (2008) Daily Functioning and Quality of Life in Children with Sickle Cell Disease Pain: Relationship with Family and Neighborhood Socioeconomic Distress. *The Journal of Pain*, **9**, 833-840. https://doi.org/10.1016/j.jpain.2008.04.002

[8] Elion, J., Laurance, S. and Lapouméroulie, C. (2010) Pathophysiology of Sickle Cell Disease. *Médecine Tropicale*, **70**, 454-458.

[9] Marsh, V.M., Kamuya, D.M. and Molyneux, S.S. (2011) All Her Children Are Born That Way': Gendered Experiences of Stigma in Families Affected by Sickle Cell Disorder in Rural Kenya. *Ethnicity & Health*, **16**, 343-359. https://doi.org/10.1080/13557858.2010.541903

[10] Mambu Nyangi Mondo, T., Malengreau, M., Kayembe Kalambayi, P. and Lapika Dimomfu, B. (2010) Delays in Seeking and Getting Care, in Seriously Ill Women of Childbearing Age in Kinshasa. *Revue d'Épidémiologie et de Santé Publique*, **58**, 189-196. https://doi.org/10.1016/j.respe.2010.02.107

[11] Tsala Tsala, J.P. (2009) Familles africaines en thérapie : Clinique de la famille camerounaise. Editions L'Harmattan, Paris.

[12] de Montalembert, M. and Niakaté, A. (2009) Approche Transculturelle du diagnostic néonatal de la drépanocytose. *Archives de Pédiatrie*, **16**, 513-514. https://doi.org/10.1016/S0929-693X(09)74049-7

[13] Graff, J.C., Hankins, J.S., Hardy, B.T., Hall, H.R., Roberts, R.J. and Neely-Barnes, S.L. (2010) Exploring Parent-Sibling Communication in Families of Children with Sickle Cell Disease. *Issues in Comprehensive Pediatric Nursing*, **33**, 101-123. https://doi.org/10.3109/01460861003663987

[14] CNRTL—ORTOLANG. (2023) Portail Lexical. https://www.cnrtl.fr/definition/

[15] Diagne, I., Ndiaye, O., Moreira, C., Stignate-Sy, H., Camara, B. and Diouf, S. (2000) Les syndromes drépanocytaires majeurs en Pédiatrie à Dakar (Sénégal). *Archives de Pédiatrie*, **7**, 16-24. https://doi.org/10.1016/S0929-693X(00)88912-5

[16] Akre, C.V., Sukhsohale, N.D., Kubde, S.S., Agrawal, S.B., Khamgaokar, M.B., Chaudhary, S.M., *et al.* (2013) Do Gender Differences Influence the Prevalence of Sickle Cell Disorder and Related Morbidities among School Children in Rural Central India? *International Journal of Collaborative Research on Internal Medicine & Public Health*, **5**, 348-358.

[17] Shongo, M.Y.P. (2014) Drépanocytose chez l'enfant lushois de 6 à 59 mois en phase stationnaire : Épidémiologie et clinique. *The Pan African Medical Journal*, **19**, Article 71. https://doi.org/10.11604/pamj.2014.19.71.3684

[18] Nacoulma, E.W.C., Sakande, J., Kafando, E., Kpowbié, E.D. and Guissou, I.P. (2006) Profil hématologique et biochimique des drépanocytaires SS et SC en phase stationnaire au Centre Hospitalier National Yalgado Ouedraogo de Ouagadougou. *Mali Medical*, **21**, 8-11.

[19] Tolo, A., Touré, A., N'dhatz, E., Nanho, D.C., Kouakou, B., Sanogo, I. and Sangare, A. (2006) Profil évolutif de la drépanocytose homozygote suivie : Expérience du service d'hématologie clinique du CHU de Yopougon. *Médecine d'Afrique Noire*, **53**, 5-10.

[20] Akodu, S., Diaku-Akinwumi, I. and Njokanma, O. (2013) Age at Diagnosis of Sickle Cell Anaemia in Lagos, Nigeria. *Mediterranean Journal of Hematology and Infec-*

tious Diseases, **5**, e2013001. https://doi.org/10.4084/mjhid.2013.001

[21] Brown, B.J., Akinkunmi, B.F. and Fatunde, O.J. (2010) Age at Diagnosis of Sickle Cell Disease in a Developing Country. *African Journal of Medicine and Medical Sciences*, **39**, 221-225.

[22] Darlison, M.W. and Modell, B. (2013) Sickle-Cell Disorders: Limits of Drescriptive Epidemiology. *The Lancet*, **381**, 98-99. https://doi.org/10.1016/S0140-6736(12)61817-0

[23] Shabbir, M. and Jalal, H. (2018) Higher Education as a Predictor of Employment: The World of Work Perspective. *Bulletin of Education and Research*, **40**, 79-90.

[24] Plan International (2022) L'education des filles, un facteur d'emancipation et de developpement. https://www.plan-international.fr/nos-combats/education-et-formation-professionnelle/l-acces-a-leducation/

[25] Laghmich, A., Ismaili, F.Z.A., Zian, Z., Barakat, A., Nourouti, G.N. and Mechita, M.B. (2019) Hemoglobinopathies in the North of Morocco: Consanguinity Pilot Study. *BioMed Research International*, **2019**, Article ID 6857417. https://doi.org/10.1155/2019/6857417

[26] Hassan, M.B., Hammam, N.A., Fuad, A.R., Bakr, H.A. and Abdulrhman, A.G. (2017) Measuring the Percentage of Consanguinity in Sickle Cell Patients and Its Effect on the Prognosis of the Disease. *Primary Health Care*, **7**, Article ID: 1000258.

[27] Denic, S., Aden, B., Nagelkerke, N. and Essa, A.A. (2013) β-Thalassemia in Abu Dhabi: Consanguinity and Tribal Stratification Are Major Factors Explaining the High Prevalence of the Disease. *Hemoglobin*, **37**, 351-358. https://doi.org/10.3109/03630269.2013.790827

[28] Cherkaoui, J.I., Chafaï, E.S., Sbiti, A., Elkerh, F., Belmahi, L. and Sefiani, A. (2009) Consanguineous Marriages in Morocco and the Consequence for the Incidence of Autosomal Recessive Disorders. *Journal of Biosocial Science*, **41**, 575-581. https://doi.org/10.1017/S0021932009003393

[29] Luboya, E., Tshilonda, J.C.B., Ekila, M.B. and Aloni, M.N. (2014) Psychosocial Impact of Sickle Cell Disease in the Parents of Children Living in Kinshasa, Democratic Republic of Congo: A Qualitative Study. *The Pan African Medical Journal*, **19**, Article 5. https://doi.org/10.11604/pamj.2014.19.5.2830

[30] Lambotte, I., De Gheest, F., Courtois, A., Delvaux, N. and Detemmerman, D. (2008) L'annonce de diagnostics graves en pédiatrie: Un processus coconstruit par les parents et les soignants. *Le Journal des psychologies*, **254**, 29-32. https://doi.org/10.3917/jdp.254.0029

[31] Lambotte, I., de Coster, L. and De Gheest, F. (2007) Le traumatisme de la mort annoncée: Transmissions entre soignants et parents face à la maladie grave d'un enfant. *Cahiers critiques de thérapie familiale et de pratiques de réseaux*, **38**, 99-115. https://doi.org/10.3917/ctf.038.0099

[32] Yugbare, S.O., Tiendrebeogo, J., Belemsaga, D., Koueta, F., Savadogo, H., Dao, L., *et al.* (2021) Evaluation du coût médical direct de la prise en charge du syndrome drépanocytaire majeur de l'enfant à Ouagadougou. *Sciences de la Santé*, **36**, 73-82.

[33] Odame, I., Kulkarni, R. and Ohene-Frempong, K. (2011) Concerted Global Effort to Combat Sickle Cell Disease: The First Global Congress on Sickle Cell Disease in Accra, Ghana. *American Journal of Preventive Medicine*, **41**, S417-S421. https://doi.org/10.1016/j.amepre.2011.09.019

Free and Informed Consent

Hello Madam, we're here as part of a study entitled **Psychological experience of mothers of children with sickle cell disease followed at the pediatric department of Bouaké University Teaching Hospital**. The study involves talking to you about your day-to-day experience, from the discovery of the disease to the management of your child's pathology. The study is aimed at all mothers of sickle-cell-affected children, regardless of nationality, gender, ethnicity, socio-professional background, etc.

Participation in the study is anonymous, confidential and voluntary. You can choose not to take part without this affecting the quality of your child's care. Your participation in the study will not be rewarded financially or materially.

If you have any questions or concerns about this study, you can ask them now. We look forward to hearing from you..

Having understood the terms of the study, I freely agree to take part in this interview.

Date..... Signature of respondent .....

SURVEY SHEET

PSYCHOSOCIAL EXPERIENCE OF MOTHERS OF ADULT CHILDREN WITH SICKLE CELL DISEASE TREATED IN THE PEDIATRICS DEPARTMENT OF UNIVERSITY HOSPITAL OF BOUAKE

Anonymity no.: /____/____/____/

Child

Age (months): ..... Gender: ..... (1 = B; 2 = G)

Nationality: ..... Ethnicity: .....

Child's position in siblings: 1) First 2) middle 3) last

Level of schooling: 1) No schooling; 2) Kindergarten; 3) Primary; 4) Secondary

Hemoglobin profile: 1) HbSS 2) HbSC 3) HbSFA2 4) HbSAFA2

Frequency of hospitalization per year: ……

Number of previous transfusions: …….

Health insurance: 1) yes 2 = no

Person living with child: 1) Parents 2) Father 3) Mother 4) Guardian

Mother

Age (year): ..... Level of education: 1) none 2) Primary 3) Secondary 4) Higher

Place of residence: …….

Ethnic group: …….

Religion: …….

Profession: …….

Number of children with sickle cell disease: ……

Marital status: 1) single 2) married 3) divorced 4) cohabiting

Consanguinity: 1) yes 2) no

Father

Age (year): ..... Level of education: 1)none 2)Primary 3) Secondary 4) Higher

Place of residence: …….

Ethnic group: …….

Religion: …….

Profession: …….

Living conditions and socio-economic level

How many children do you have? .....

Type of dwelling: 1) Detached villa 2) Common courtyard 3) Family home

Do you have access to? 1) Electricity 2) Water

What is your monthly family income? 1) Less than 25,000 2) 25,000 - 50,000 3) 50,000 - 100,000 3) 100,000 - 200,000 4) 200,000 - 300,000 5) 300,000 - 400,000 6) 400,000 - 500,000 7) more than 500,000

What is the monthly income of the child's father? 1) Less than 25,000 2) 25,000 - 50,000 3) 50,000 - 100,000 3) 100,000 - 200,000 4) 200,000 - 300,000 5) 300,000 - 400,000 6) 400,000 - 500,000 7) more than 500,000

Disease and diagnosis

Circumstances of discovery: 1) incidental 2) hospitalization 3) genetic counseling

Age of onset: .....

In your opinion, what are the causes? 1) Genetic 2) infectious 3) supernatural

At first, do you think it was a serious illness? 1) yes 2) no

Diagnosis announcement

Was the announcement clear and complete in your opinion 1) Yes 2) No

Was it made in the presence of both parents? 1) Yes 2) No

1) In the consultation room with other patients present 2) In the hospital ward with other patients present 3) In the doctor's office

Did you know anything about the disease or had you ever heard of it? 1) Yes 2) No

What feelings did you have at the time? 1) Powerlessness 2) Guilt 3) Discouragement 4) Sadness 5) Shame 6) Shock

What was your reaction 1) Anxiety 2) Depression 3) Aggression 4) Indifference

What was your vision for your child's future at this time? 1) Hope of recovery 2) incurable disease 3) fatal outcome

Care and treatment

Who paid the medical expenses? 1) father 2) mother 3) family 4) Friends or neighbors

Did you use a traditional practitioner? 1) Yes 2) No

Were you offered psychological counselling? 1) Yes 2) No

If not, would you have liked to have had one? 1) Yes 2) No

Psychological and social aspects

How did you see your child? 1) Love 2) Sadness 3) Pity 4) Other

Have you talked about your child's illness to anyone around you?

1) YES

- Other family members
- Colleague
- Friends/neighbors

2) No and why

- Fear of others
- Other, please specify

How did others look at your child? 1) Support 2) Rejection 3) Pity 4) Other, please specify: .....

Were you given moral support?

1) If yes, by whom: a) Spouse b) Other family member c) Neighbors and friends

2) No

Have you experienced any marital problems as a result of your child's illness?

1) If yes, which ones

- Arguments
- Separation
- Divorce
- Abandonment

2) No

Did your child feel different from others?

1) If yes, how did he manifest this?

- Muting
- Isolation
- Other, please specify

2) No

Costs and expenses

Have you interrupted your activities? 1) Yes 2) No

Does the child's illness have an impact on the couple's savings? 1) Yes 2) No