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# Knowledge, Attitudes and Practices of Parents in the Vaso-Occlusive Crises of the Sick Children in Brazzaville

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#### **Abstract**

Objectives: to evaluate the parents' knowledge of vaso-occlusive crises, to identify their attitudes and practices. Method: a retrospective, transversal, descriptive and analytical study carried out between January and June 2016 at the HUC of Brazzaville. The parents of sickle cell children aged 2 to 17 years, followed for at least one year, were interviewed. Results: a total of 319 parents were interviewed, including 221 women (69.3%) and 98 men (30.7%) with a mean age of 40.8 ± 9 years. They were unschooled 65 cases (20.4%), had primary education 41 cases (12.9%), secondary 149 cases (46.7%) and higher level 64 cases (20.1%). They had one child sickle cell 258 cases (80.9%). They knew sickle cell disease 283 cases (88.7%), its genetic transmission 249 cases (78.1%). The source of information was a health worker 211 cases (66.1%). They had a good knowledge of the vaso-occlusive crisis 101 cases (31.7%). In a vaso-occlusive crisis, they used a health facility 207 cases (64.8%), self-medicated 66 cases (20.7%). Their home practices were good 99 cases (31%), fairly good 135 cases (42.3%) and bad 85 cases (26.5%). Parents aged 25 to 34 (OR = 1.8 95% 1 - 3), secondary (OR = 1.7 95% 1 - 2.7) and with good practices (OR = 4.5 95% 2.7 - 7.5) are those who have a good knowledge of vaso-occlusive crises. Conclusion: The importance and severity of vaso-occlusive crises in the sickle-cell child's life experience, the crucial role played by parents in their care requires that the information, education and communication of these children be strengthened To improve their quality of life.

## **Keywords**

Sickle-Cell Disease, Vaso-Occlusive Crises, Children, Knowledge,

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#### Attitudes, Practices, Brazzaville

#### 1. Introduction

Sickle cell anemia, a hereditary disease related to a hemoglobin abnormality, is a public health problem [1] [2]. According to the World Health Organization (WHO), nearly 120 million people worldwide, or about 5% of the population, carry the sickle cell trait and 500,000 children are born each sickle cell year, of which 200,000 in Africa [2].

In Africa, 10% - 40% of the population would carry the sickle cell trait and about 2%, homozygous [3].

In Congo, sickle cell disease varies between 20.7% and 23.5% and 1.2% of the population is homozygous [4].

Sickle cell anemia has a highly polymorphic and noisy clinical translation dominated by acute vaso-occlusive crises, the leading cause of sickle cell child morbidity [5]-[11]. Its management, currently well codified, rests among others on awareness, prevention and early detection [12].

The prevention of vaso-occlusive crises, an essential component of the secondary prevention of sickle cell disease, requires that the clinical manifestations, preventive measures and factors favoring the prevention of sickle cell disease are known to parents and sickle cell children.

To improve the quality of life of sickle-cell children, the objectives of this study were to assess parents' knowledge of vaso-occlusive crises, to identify their attitudes and practices in the face of vaso-occlusive crises.

# 2. Methodology

It was a retrospective, transversal, descriptive and analytical study carried out between January and June 2016, in 6 months, in the unit of follow-up of sickle-cell children of the Hospital and University Center (HUC) of Brazzaville.

Parents with homozygous sickle cell children aged 2 to 17 years who have been followed for at least 12 months and who have agreed to participate in the study have been included.

The selection of parents was made after a simple random draw. The sample size was calculated from the Schwartz formula:

$$N = t^2 \times p \times (1 - p) / e^2$$

t: reduced risk difference  $\alpha = 5\%$  (corresponding to 1.96); e: margin of error set at 0.05; p: prevalence of homozygous sickle cell disease = 2%.

A total of 319 parents meeting the inclusion criteria were selected.

The study variables were:

- Those related to the parents: age, sex, educational level and marital status;

- Those relating to knowledge of sickle cell disease: the definition of sickle cell
  disease, the definition was good when it included the items "hereditary disease or blood disease", the mode of transmission, the source of information,
  clinical manifestations, Screening examinations, complications, preventive
  measures, signs requiring emergency consultation;
- Those relating to the knowledge of vaso-occlusive crises: their locations, clinical expression, triggers and means of prevention;
- Those relating to the attitude of parents to a vaso-occlusive crisis: the first-line appeal structure;
- Those relating to the quality of the parents' home practices in the face of a vaso-occlusive crisis.

### 2.1. Criteria for Judgment

In order to assess parental knowledge of vaso-occlusive crises, a grid was developed that included the following parameters (location, clinical manifestations, preventive measures and triggers). These parameters were composed of items rated at 1 each (Table 1) and the assessment of the overall knowledge of vaso-occlusive crises (Table 2).

Table 1. Level of knowledge of parents of vaso-occlusive crises.

	Omate		Knowledge		
	Quote	Good	Average	Low	
	Locati	ion			
Bone	1	2	1	0	
Abdominal	1	2	1	U	
	Clinical mani	ifestations			
Pains	1	2	1	0	
Swelling	1				
Favorable factors					
Cold	1				
Fever	1				
Dehydration	1				
Stress	1	2 = (5 - 7)	1 = (2 - 4)	0 = (< 2	
Physical effort	1				
Beaten	1				
Infection	1				
Preventive measures					
Warm clothing	1				
Drinks abundant	1	2 (2 1)	1 = (2)	0 = (<2	
Intense physical effort	1	2 = (3 - 4)			
Use of mosquito net	1				

Table 2. Overall knowledge of vaso-occlusive crises.

Overall knowledge of vaso-occlusive crises					
<b>T4</b>	Quote	Knowledge			
Items		Good	Average	Low	
Location	0 - 2		5 – 3	<3	
Clinical expressions	0 - 2				
Factors triggering	0 - 2	6 - 8			
Means of prevention	0 - 2				

In order to evaluate the practices of the parents at home, our criteria were as follows: the practice was said to be good when the parents used the three therapeutic means: hyper hydration, analgesics and anti inflammatory and/or anti spasmodic, Good enough for those who used two of these therapeutic means and bad for those who did not use any therapeutic means.

#### 2.2. Ethical Considerations

The study protocol obtained the approval of the Committee of Ethics of Health Sciences Research: N°041/MRSIT/IRSSA/CERSSA.

#### 2.3. Statistical Analysis

The data mask, data processing and analysis were performed using SPSS software version 19 and Excel 2010. The statistical analysis was performed at two (2) levels: a univariate analysis to determine the frequency of each variable and A bi or multi varied to study the associations between the variables. Qualitative data, proportions and their associations were performed through the contingency tables with their significance measured by the Pearson chi-square test. Risk quantification was assessed by estimating the odds ratios (Odd-Ratio) with their 95% confidence intervals. However, a Pearson correlation was required to verify the existence or not of a relationship between a dependent variable Y considered independent with a dependent variable X. The *p* value of the probability was judged to be significant for a value less than 0.05. Any exposure of an event to an Odd-ratio greater than 1 with a probability of less than 5% was considered to be at risk or high risk.

#### 3. Results

#### 1) Socio-Demographic Characteristics of Parents

The study population consisted of 319 parents aged an average of  $40.8 \pm 9$  years (25 and 60 years). There were 221 women (69.3%) and 98 men (30.7%), unschooled 65 cases (20.4%), with primary education 41 cases (12.9%), Secondary education 149cases (46.7%) and higher level 64 cases (20.1%). They were married 214 cases (67.1%), singles 88 cases (27.6%), widows 10 cases (3.1%) and divorced 7 cases (2.2%). They had one child with sickle cell disease 258 cases

(80.9%), two children 30 cases (9.4%), three children and more 31 cases (9.7%).

#### 2) Knowledge of Sickle Cell Disease

Sickle cell disease was known by 283 parents (88.7%), the definition given was good 258 cases (80.9%). The known mode of transmission was genetic 249 cases (78.1%). Hemoglobin electrophoresis was performed in 151 cases (47.3), Seriver Vaugh 95 cases (29.8%), Emmel 66 cases (20.7%). Sixty-eight (68) parents (21.3%) had no screening for sickle cell disease. The parents' source of information was a health worker 211 cases (66.1%), the media 71 cases (22.3%), the family 50 cases (15.7%) and the school 35 cases (11%).

Clinical manifestations were pain 254 cases (76.9%), fever 185 cases (58%), jaundice 170 cases (53.3%), swelling of the Hands and/or feet 151 cases (51.3%), anemia 149 cases (46.7%), and the delay of weight and height 80 cases (25.1%). Thirty-seven parents (11.6%) had no knowledge of the clinical manifestations of sickle cell disease.

The known complications were bone pain and anemia 99 cases (31%) each, leg ulcer 58 cases (18%), osteonecrosis of the femoral head 49 cases (15.4%), stroke 33 cases (10.4%) and priapism 20 cases (6.3%). One hundred and fifty-five (48.6%) parents had no knowledge of the complications of sickle cell disease. The means of preventing sickle-cell anemia cited by the parents were: the obligation of the prenuptial assessment 222 cases (69.6%), the prohibition of consanguineous marriages 153 cases (47.9%) and the screening before pregnancy 134 cases (42%).

The signs requiring urgent consultation were pallor 225 cases (70.3%), fever 202 cases (63.3%), pain resistant to analysesics 201 cases (63%), an increase in the volume of the abdomen 168 cases (52.7%) and a change in staining of urine 163 cases (51.1%).

#### 3) Knowledge of Vaso-Occlusive Crises

The level of knowledge of localization, clinical expression, triggering factors, preventive measures and assessment of the overall knowledge of vaso-occlusive crises in the study population are shown in **Table 3** and **Table 4** and **Figure 1**.

Table 3. Knowledge of vaso-occlusive crises.

Knowledge of CVOs	Good	Average	Low
Location	199 (62.4%)	83 (26%)	37 (11.6%)
Clinical manifestations	6 (1.2%)	186 (58.3%)	127 (39.8%)
Favorable factors	88 (27.6%)	135 (42.3%)	96 (30.1%)
Preventative measures	104 (32.6%)	112 (35.1%)	103 (32.3%)

Table 4. Overall knowledge of vaso-occlusive crises.

	Good	Average	OR	OR a	P
[25 - 34]	32	45	1.8 [1 - 3]	0.6 [0.4 - 1.1]	0.03207
Secondary	56	93	1.7 [1 - 2.7]	0.4 [0.3 - 0.6]	0.03326
Good practices	74	25	2.1 [1.2 - 3.8]	4.5 [2.7 - 7.5]	0.0000

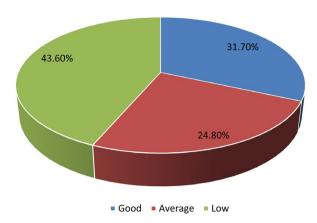


Figure 1. Overall knowledge of vaso-occlusive crises.

#### 4) Parental Attitudes and Practices in the Face of a Vaso-occlusive Crisis

During a vaso-occlusive crisis, parents used a health facility in 207 cases (64.8%), self-medicated 66 cases (20.7%) and administered traditional treatment 46 cases (14.5%). For those who consulted a health facility, their choice was in all cases guided by the quality and the existence of free treatment. The remoteness of the health facility, the cumulative experience in the management of sickle cell disease and the cost of hospitalization were reasons for not using a health facility.

Therapeutics administered at home were: abundant hydration 174 cases (54.5%), analysesics 174 cases (72.1%), anti-inflammatory and/or antispasmodic 226 cases (70.9%), massages and applications of hot towels 59 cases (18.5%).

Practices at home were considered good (31%), average (42.3%) and bad (26.7%).

#### 5) Knowledge Determinants

The determinants of knowledge of vaso-occlusive crises and their locations are shown in **Table 4** and **Table 5**.

#### 4. Discussion

The aim of this study was to assess the parents' knowledge of a vaso-occlusive sickle cell crisis, to identify their attitudes and practices in the face of vaso-occlusive crises.

From a sample of 319 parents divided into 221 women and 98 men, knowledge of sickle cell disease is required for 283 of them (88.7%). The main known mode of transmission is genetic 249 cases (78.1%). Knowledge of the vaso-occlusive crisis is good for 101 parents (31.7%). The age range of 25 to 34 (OR =  $1.895\% \ 1 - 3$ ), secondary education (OR =  $1.795\% \ 1 - 2.7$ ), and good Practices (OR =  $4.595\% \ 2.7 - 7.5$ ) are the determinants of knowledge. Home practices are good 99 cases (31%), fairly good 135 cases (42.3%) and bad 85 cases (26.5%).

## 1) Sociodemographic Profile of the Study Population

The child sickle cell in Brazzaville is willing to pay the mother (69.3%). This is a constant in Africa, as reported earlier by us, Sangho *et al.* in Mali and Zola laina

**Table 5.** Knowledge of the location of vaso-occlusive crises.

	Knowledge of CVO location							
	Good	Average	OR	ORa	P			
25 - 34	62	15	3.2 [0.3 - 1.3]	1.6 [0.9 - 2.9]	0.10564			
Male	73	25	2.2 [1.3 - 3.7]	1.1 [0.7 - 1.8]	0.70765			
Superior	54	10	4.1 [2.4 - 12.8]	2.2 [1.1 - 4.3]	0.02806			
1 child	175	83	3.3 [2.5 - 13.5]	0.6 [0.4 - 0.9]	0.00787			

et al. in Madagascar [12] [13]. The usual proximity of mother and child on the one hand, and popular beliefs in Africa on the other, beliefs that the transmission of blood diseases is closely linked to the mother, justify their being guilty [14] and thus made responsible for their care.

The mean age of the parents estimated at 40.8 years in this study is like that reported by Assimadi *et al.* [15]: 39.6 years. Sangho *et al.* [12] report a younger population.

Parents have a secondary level in 46.7% of the cases and not in school 20%, as in Togo: 34.9% of secondary level and 16% not schooled. On the other hand, in Madagascar, Zola Laina reports 60% of parents of secondary level and 4.4% of not schooled.

All the authors [12] [16] [17] agree that the parents in charge of the sickle cell child live in a couple as observed in 67.1% of the population of this study. However, fear and refusal of maternity after the discovery of the disease in the first child explain why 80.9% of these in Brazzaville and 69.5% in Togo [15] have only one child sickle cell. Eloundou *et al.* [17] noted the existence of a sickle cell child in 35% of cases, Dione *et al.* [18]: 30% and Diallo *et al.* [19]: 31%.

## 2) Knowledge of the Vaso-occlusive Crisis

Knowledge of the vaso-occlusive crisis in Brazzaville is poor for 66.6% of parents, yet their main source of information is a health worker (66.1%) (OR = 4.5 95% 1 - 2.7) and having good practices (OR = 4.5 95% 2.7 - 7.5). Parents aged between 25 and 34 (OR = 1.8 95% 1 - 3), a secondary education (OR = 1.7 95% 1 - 2.7) and having good (OR = 4.5 95% 2.7 - 7.5) have a significant knowledge of the vaso-occlusive crisis. It is also noted that having a sickle cell child (OR = 3.3 95% 2.5 - 13.5) and higher education (OR = 4.1 95% 2.4 - 12.8) influence Knowledge of the location of the vaso-occlusive crisis. And having more than one sickle cell child (OR = 4.9 95% 0.9 - 27.9) improves knowledge of clinical manifestations. However, for Sangho *et al.* [12], the high level of education of mothers does not influence the knowledge and quality of management of vaso-occlusive crises. Knowledge of the factors favoring vaso-occlusive crises, an important aspect of prevention is good: 69.9%. Exposure to cold is the most common factor (40.4%). In Mali [18], knowledge of favorable factors is good for 78.6% of mothers.

#### 3) Parents' Attitudes to a Vaso-Occlusive Crisis

In a vaso-occlusive crisis, the use of a health facility is 64.8% of the time. Rec-

ognition of the UHCB as a center of reference and the effectiveness of free care justify this choice. But despite this good adhesion, the practice of self - medication and the use of traditional healers are noted in 14.5% of the cases.

#### 4) Parents' Practices in the Face of a Vaso-Occlusive Crisis

This work shows that only 31% of parents have good practices. As knowledge of vaso-occlusive crises influences the practice (OR = 4.4, 95% 2.7 - 7.5), it is permissible for the rules of good practice to be taught at any consultation of the sickle cell child.

#### 5. Conclusion

It follows from this study that parents have a poor knowledge of vaso-occlusive crises. The sickle cell follow-up unit is the first resort. Practices at home before a vaso-occlusive crisis are generally poor. The factors influencing knowledge of vaso-occlusive crises are: the age of parents between the ages of 25 and 34 years, secondary education and good practice.

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