

## Health Education of the Sickle Cell Disease Patient: Knowledge and Practical Attitudes of 186 Sickle Cell Patients Concerning Ophthalmologic Checking In Abidjan

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### ABSTRACT

**Introduction:** Due to the blindness risk from sickle cell retinopathy, regular ophthalmological monitoring of sickle cell patients is required. The aim of this study was to contribute to a better understanding of the determinants of the adhesion of SCD patients to ophthalmologic disease surveillance.

**Results:** Of 186 patients in total, 123 were women (2 women/1 man) aged from 15 to 65 years (mean 31.5 years). The average age of diagnosis of sickle cell anemia was 17.88 years and the first monitoring ophthalmologic consultation was held on average at 22.5 years. Only 26 patients (13.98%) had a satisfactory score, regarding the level of knowledge about sickle cell disease and its ocular complications. The age group of 30 to 44 years had the highest score. The medium score was statistically linked to genotype as SS patients had the highest score while AS patients had the lowest score. Of 110 patients who had received at least one consultation in ophthalmology, only 60 had conducted it as part of the ophthalmologic monitoring of sickle cell disease. 49 of 60 patients said they had spent more than 2 years without ophthalmologic consultation surveillance. Of 186 patients, 33 (17.74%) had spoken about the sickle cell disease eye complications with their hematologists and only 13 (7%) had done the same with their ophthalmologists.

**Conclusion:** Inadequate communication between caregivers and patients is a cause of health's miseducation thereof resulting in poor adhesion to the ophthalmologic monitoring of sickle cell disease.

### Keywords

Sickle Cell Disease (SCD), Retinopathy, Ophthalmologic monitoring, Health education.

### Introduction

Sickle cell disease is a genetic disorder of red blood cells caused by a structural abnormality of the globin molecule. This anomaly results from the replacement of the glutamic acid by valine at position 6 of the beta chain of globin. Abnormal beta chains formed give hemoglobin "S" while normal beta hemoglobin chains form hemoglobin "A" [1]. Sickle cell retinopathy is the vascular consequence of the alteration of the red cell due to the

polymerization of deoxygenated hemoglobin "S". It becomes very insoluble and precipitates in the red blood cell. It loses its flexibility and takes the form of a sickle it is called "the sickling". Triggered by local hypoxia or acidosis, sickling can lead to vascular occlusions in the peripheral retinal circulation, mainly in the pre-capillary arterioles and capillaries. The retinal ischemia will cause sickle cell retinopathy with complications such as intra vitreous bleeding and tractional retinal detachment that can lead to irreversible vision loss [1,2]. However, complications of sickle cell retinopathy are not inevitable. Indeed, through the routine screening, these complications can be prevented by a laser photocoagulation of retinal ischemic territories [3,4]. Thus,

routine screening and early treatment of sickle cell retinopathy represent the cornerstone of the fight against blindness related to sickle cell disease, especially in a limited resources context but with a high prevalence of the disease, such as ours. Indeed, the frequency of the sickle cell gene is estimated at 5 to 20% in Africa and would reach 40% of the population in some areas in Central Africa [5]. Sickle cell disease is very common in our environment. But what do sickle cell patients know about their disease and its complications, including eye? Furthermore, what impact this knowledge could have on their attitudes regarding ophthalmologic monitoring of the disease? The aim of this study is to contribute to a better understanding of the determinants of patient adherence to the ophthalmologic monitoring of sickle cell disease.

## Method

This is a transversal prospective study that lasted three months (August 1st to October 31st, 2011) conducted in the Immunology-Hematology departments of University Hospital Centers (CHU) of Cocody and Yopougon, in Abidjan (Côte d'Ivoire). We systematically recruited sickle cell patients, all forms included, aged of 15 and more. It was outpatients from immuno-hematology departments of these hospitals during the period of investigation. These patients came either for personal reasons or accompanying one of their children or relatives. The exclusion criteria were: age less than 15 years, patients diagnosed and followed for less than 6 months, patients in whom the language barrier prevented the understanding of the survey sheet and patients that were working at the services where the study took place. Informed consent from respondents was obtained by verbal agreement after explanation of the interest of the study and ensuring the confidentiality of responses and anonymity of survey forms. Of 275 patients identified, 186 were selected for the study.

The following data were studied:

- Socio-demographic data: age, gender, level of education and socio-professional activity;
- History of the disease: age at diagnosis, circumstances of diagnosis, age at the first consultation hematological monitoring and the age at the first ophthalmologic consultation surveillance;
- The form of sickle cell disease (phenotype / genotype);
- The patient's knowledge about the disease, firstly and secondly on its ocular complications;
- Practical attitudes vis-à-vis the ophthalmologic monitoring patients.

Data were collected on individual and anonymous survey forms and were treated using Stata software. We did not use standardized questionnaire. We arbitrarily selected questions that we believe reflected a "minimum package of knowledge and attitudes" that could promote patient adherence to the ocular monitoring of sickle cell disease. For each question we assigned a score arbitrarily assuming that all questions were equivalent to each other and therefore, had the same score. Questions regarding the level of knowledge were entitled to 1 point for a correct answer and 0 points for a wrong answer or no answer. The different scores have

been reported to 100 in order to define three levels of knowledge:

- Insufficient score: strictly less than 50;
- Average score: between 50 and 75;
- Satisfactory score: strictly greater than 75.

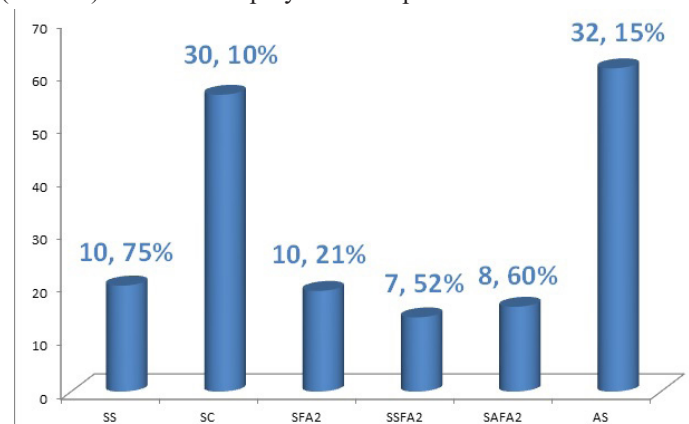
Descriptive data were subject to many calculations such as proportions, means, variances, and standard deviations. Those data were presented in tables or figures. Analytically, the Chi 2 test was used with a significance level of 5%.

## Results

### Descriptive data

#### Sociodemographic characteristics of the study population and phenotypic profile

The 186 patients were consisted of 123 women (66.13%) against 63 men (33.87%) or about 2 women to 1 man; all aged from 15 to 65 years (mean 31.5 years with a standard deviation of 10.65). The most represented phenotypes were the SC and AS which represented 62.9% of the sample (Figure 1). The mean age at the time of the diagnosis of sickle cell anemia was 17.88 years (range 10 months to 47 years with a standard deviation of 11.21). The discovery of the disease was made when patients were facing complications in 60.22% of cases, or during a checkup prompted by the occurrence of a complication among some relatives in 27.42 % of cases. The accidental discovery of sickle cell disease was made only in 4.30% of cases. The first hematologic control consultation was made at an average age of 14.5 years (range 1 year and 46 years old) while the first ophthalmologic surveillance consultation had occurred at the mean age of 22.5 (range 12 years and 40 years). The majority of patients had a high school education level (101 patients or 54.30%), followed by the university level (50 patients or 26.88%). Those with primary level were 29 (15.59%) and 6 patients were illiterate (3.23%). Regarding the socio-professional status, 88 patients (50%) were in the study field at various levels such as primary level (42 patients or 22.58%), university students (22 patients or 11.83% patients) and teachers (24 patients 12.9%). The other half consisted of merchants (19.89%), professionals from a sector called "informal" such as hairdressers, dressmakers (18.60%) and the unemployed who represented about 14%.



**Figure 1:** Distribution according to the genotype- Distribution of patients according to the form or the genotype of sickle cell.

The most represented in our sample forms are the SC (30,10%) and AS (32,15%) forms. These two forms represent (62,25%) of all patients.

## Knowledge about the disease and its ocular complications

Regarding the knowledge of the disease, most patients said it was hereditary (89.25%), it was not contagious (86.56%), it could cause complications (86.56%) and the most known complications were bone complications (86.34%).

Sickle cell disease was considered as not being curable by more than half of the patients (68.28%) and almost all knew that there were several types of sickle cell disease (98.39%). On racial distribution of the disease, only 95 patients (51.08%) said that there was a racial predominance and 93 of them have indicated the black race as the most affected. 132 patients (70.97%) said that it was possible to prevent sickle cell crises and the well-known crises triggers were physical effort (73.66%), cold (70.43%) and fever (58.06%). The risk factor between pregnancy and sickle cell crises was recognized by 88 patients (47.31%). The disease could be life threatening in the opinion of 153 patients (82.26%) and required life or chronic surveillance (74.42%) and regular medical consultations (95.70%). Regarding the prevention of the transmission of sickle cell disease, it was considered possible by 103 patients (55.38%) however, 83 of them (80.58% of 103) asserted that prevention could be handled through some medications. The remaining 20 patients (19.42%) mentioned the premarital checkup and the abandonment of consanguineous marriages as prevention methods. Almost all the patients had never heard of antenatal nor neonatal screening or bone marrow transplantation as treatment options of sickle cell disease.

Regarding the ocular complications of sickle cell disease, 123 patients (66.13%) said that they were possible; however 87 of them did not know what could be those complications. Only 6 patients said that these complications were retinal (representing 3.23% of the whole patient sample). In addition, 49 patients out of 123 (39.84%) said that the ocular complications of sickle cell disease could lead to permanent vision loss (representing 26.34% of the whole patient sample), 35 patients over 123 (28.46%) said that there is a link between these ocular complications and the genotype of sickle cell; and 11 of 123 patients (9% but only 6% if based on all patients sample) knew that the SC was the type leading the most to eye complications. Of 123 patients who had recognized the possibility of ocular complications, the majority (103 over 123 or 86.18%) thought that ophthalmologic surveillance consultation were necessary, 90 (73.17%) did not know whether these ocular complications could be avoided and only 39 patients (31.71%) knew that the examination of the fundus allowed to detect eye complications. The sources of knowledge regarding eye complications from sickle cell were represented respectively by the doctor for 48 patients (39.02%), the entourage for 49 patients (39.83%). The remaining 26 of 123 patients (21.15%) were informed through other sources such as the media. A slight majority (105 or 56.45%) had a medium score, only 26 patients (13.98%) had a satisfactory score and nearly one third of patients had a score considered insufficient (29.57%) when it came to the level of knowledge.

Patient practical attitude regarding the ophthalmologic monitoring

Of the 186 patients, 119 (63.98%) were followed in hematology services but among them, more than half (56.30%) had acknowledged having spent more than a year without honoring their appointments in hematology. The remaining 67 (36.02%) who weren't monitored were essentially AS patients, relatives and companions of sick children during the hematology consultation. Of 110 patients who had done at least one consultation in ophthalmology (59.13% of 186 patients), 60 patients had made this consultation as part of the ophthalmologic monitoring of SCD recommended by their doctors (less than 1 / 3 of the sample); in addition, 49 of those 60 patients said that they spent more than 2 years without ophthalmologic consultation surveillance. The frequency of ophthalmologic monitoring consultations was annual for 16 patients, biannual for 10 patients and 30 patients had achieved eye clinic monitoring no more than twice, since the discovery of the disease; corresponding respectively to 26.67%, 16.67% and 50%. Reported to the whole sample, these rates respectively turn into 8.60%, 5.37% and 16.12%. Five patients out of 186 (2.69%) had carried out a retinal angiography during their ophthalmologic monitoring. Only 33 of 186 patients (17.74%) had addressed the issue of ocular complications of sickle cell disease with their hematologist. Among the 110 patients who had made at least one ophthalmologic consultation, only 13 had raised this issue with the ophthalmologist. Moreover, the time between the first ophthalmologic monitoring consultation and the first consultation in hematology was over 3 years for 44 patients, representing 73.33% of the 60 who had, at least, one ophthalmologic consultation surveillance.

## Analytical Data

Statistical analysis showed a significant association between the score and the age group, the age group of 30 to 44 had the best knowledge level score (Table 1). There was no link between the education level of the patients and the score (Table 2). The medium score was statistically related to the genotype: SS patients had the highest score while AS patients had the lowest score (Table 3 and Table 4). The discovery of the disease through personal complications was significantly linked to the genotype in the following order: SS (94.73 %), SSFA2 (85.71 %), SAFA2 (81.25 %), SFA2 (78.94 %) and SC (78.51 %) (Table 5). There was a statistical link between the average age of the discovery of the disease and genotype: earlier in SS patients and much later in AS patients (Table 6).

		Age class			Total
		15-29	30-44	> 45	
Scores	Insufficient	27	24	4	55
	Way	51	43	11	105
	Satisfactory	9	9	8	26
Total		87	76	23	186

**Table 1:** Correlation between scores and age class.

Chi2 = 9,8877 = (4) Pr = 0.042 ddl

In patients with a score that is satisfactory, the average age was of 36.5 (and = 13, 18) with extremes ranging from 15 to 65.

There was a statistically significant relationship between the score and

the age group.

	Level of studies				
	Illiterate	Primary	Secondary	University	Total
Insufficient	2	14	30	9	55
Way	3	15	55	32	105
Satisfactory	1	0	16	9	26
Total	6	29	101	50	186

**Table 2:** Correlation between score and level of education.

Chi2 = 11, 37 DDL = 6 P = 0,077.

There is a statistical link between the score received by the patients and the level of studies.

Type	Average score	Standard deviation	Minimum	Maximum
SS	62,06897	15,74247	31,03448	86,20689
SC	60,79183	16,05266	20,68966	86,20689
SFA2	54,26497	15,58487	24,13793	82,75862
SSFA2	52,95566	16,26448	17,24138	75,86207
SAFA2	58,83621	17,42289	17,24138	86,20689
ACE	52,79819	17,56637	17,24138	86,20689

**Table 3:** Average Score of patients according to the shape or the genotype of sickle cell disease.

The highest average score was assigned to the SS patients or 62.06; AND = 15, 74.

Conversely, AS patients had a low average score compared to the study population overall is 52,79; AND = 17.56.

Scores	Genotypes						Total
	SS	SC	SFA2	SSFA2	SAFA2	ACE	
Insufficient	4	13	6	5	4	23	55
Way	12	32	11	8	10	32	105
Satisfactory	4	11	2	1	2	6	26
Total	20	56	19	14	16	61	186

**Table 4:** Correlation between the score class and the shape or the genotype of sickle cell disease (Total).

Chi2 = 10,37 ddl = 5 p = 0, 080.

There was no statistically significant relationship between genotypes and obtained scores classes. However, 43.40% of subjects with a score considered insufficient were ACE.

Genotype	Circumstances of the discovery of the disease					Total
	Fortuitous	Balance sheet	Complications	Other	Complications	
SS	0	0	19	0	1	20
SC	2	2	44	0	8	56
SFA2	0	0	15	0	4	19
SSFA2	1	0	12	0	1	14
SAFA2	2	1	13	0	0	16
ACE	3	8	7	4	39	61
Total	8	11	110	4	53	186

**Table 5:** Correlation between circumstances of diagnosis and genotypes.

Chi2 = 102,4198 ddl = 20 p = 0.00000.

There was a highly significant statistical link between the shape of sickle cell disease and its diagnosis during a personal complication.

Genotype	Age way	Standard deviation	Maximum	Minimum
SS	8.65	8,279811	35	1
SC	16,1852	8,868162	34	1
SFA2	11,8947	12,45306	47	5
SSFA2	9,92857	7,508603	22	1
SAFA2	18,125	10,10528	43	5
ACE	26,2951	8,956086	45	5

**Table 6:** Correlation between mean Age at the diagnosis of sickle cell disease and genotypes.

Chi2 = 9.88; DDL = 4; p = 0.042

There was a statistically significant link between the average age of discovery of the disease and the genotype: the average age of diagnosis was earlier at the patients SS 8.65 years (or = 8, 27) and much later in patients AS 26,29 years (and = 8, 95).

## Discussion

### Descriptive data

#### Socio-demographic characteristics of the study population

The patients included in our study were aged from 15 to 65 with an average of 31, 5 years, close enough to what Balo study found in Togo [6] and Asnani in Jamaica [7]. The relative youth of this population could be explained by the structure of the Ivorian population as described by the National Institute of Statistics, namely a predominantly young population [8]. The females are predominantly found in many studies [6,7,9,10] as it was the case in ours. It could also be explained by the female proportion in the general population [8,9]. However, other authors believe it may also be explained by the improvement in survival of female patients with sickle cell disease, unlikely male patients [11]. In proportions such as we found (2 women for 1 man), we believe that there has been a selection bias. Indeed, in our context, mothers are almost always the only one accompanying the sick children to the hospital. These mothers usually from AS genotype, conductive, less symptomatic and accompanying of sick children who were included in the study could have led to increase the female proportion.

The patient education level found in our study could be explained by the fact that the study was conducted in an urban context: secondary school (54.30%) and university (26.88%). This trend was also seen for occupational category for which almost half of the sample was composed of high school students, university students and teachers. Moreover, the negative impact of sickle cell disease morbidity on the education, of the first categories as mentioned by Jenifer M et al. [12], could motivate their greater tendency to attend health centers in search of a better wellbeing that could lead to a schooling less affected by the disease. The mean age at the time of diagnosis appeared late and could be explained by the level of knowledge about the disease in the general population [10] and the absence of a systematic screening policy. The differences between the different genotypes are due to the variability of symptoms depending on the genotype and our study found a link between the average age at diagnosis and genotype: the average age of discovery of sickle cell anemia was the latest in subjects with AS genotype and this discovery was done mostly through the complication that occurred to a close relative. Yet,

these AS subjects are clearly identified as being the essential link in the tale transmission of the disease, through screening. [9] This fact justifies once again the crucial need for a systematic screening program.

### Attitudes and practical knowledge level

The level of knowledge of sickle cell disease is relatively good among the SCD patients compared to the level of knowledge about the disease in the general population [10]. However this level seems insufficient as regards the preventing methods of the transmission of sickle cell disease and the prevention of its ocular complications. This may explain the low adherence of patients to the ophthalmologic monitoring of sickle cell disease. Our study reveals that either the poor or the lack of communication from medical staff about the disease and its complications is the main cause of this knowledge gap. Indeed, among the 123 patients (of 186) who knew the existence of ocular complications, 48 (39.02%) had learned it from doctors and almost as much (49 patients) did the same but from the entourage. The information gap from the medical staff is further emphasized by the fact that, 33 (17.74%) from all the patients had addressed the issue of ocular complications of sickle cell disease with the hematologist and from the 110 who had done at least one ophthalmologic consultation, only 13 (11.81% of 110) had raised this issue with the ophthalmologist.

These findings highlight the relevance of real determinants of patient adherence to both chronic disease treatments and their monitoring in our context. Although inadequate resources are an undeniable reality, isn't it an excuse too easily evoked? Indeed, Ouattara and col. after assessing the ophthalmologic monitoring of a cohort of 1,200 diabetics from the Anti-diabetic Centre in Abidjan over a period of 5 years, found at the end of these 5 years only 46 diabetics, (a rate of loss of 96.16%). Among these 46 patients, 25 had made only one monitoring eye examination over 5 years (54.34%), 10 had achieved 2 (21.71%), 9 had achieved 3 (19.56%) and 2 had achieved 4. Thus, there was an average of 2 monitoring eye examinations over 5 years for the remaining 46 diabetics in the original cohort of 1,200 [13]. To understand this poor patient adherence to diabetes monitoring, another study was conducted by the same authors in the same center. Of 309 diabetics of this study, virtually all (298 or 94.4%) said that they had never heard of diabetic retinopathy and only 131 patients (42.4%) had received ophthalmologic consultation with at least one fundus monitoring since the discovery of diabetes. And among these, 97 (74%) had said that he had never spoken of ocular complications of diabetes with their ophthalmologists. As a result, 197 diabetics (63.8%) had no opinion regarding the relevance of the fundus examination in diabetic patients [14].

These two studies highlight the poor level of health education on diabetes and diabetes complications including eye. This could explain their low adherence to the ophthalmic disease surveillance. The low adhesion of SCD patients to ophthalmologic monitoring of sickle cell disease as revealed by this study could also be the result of poor health education on the disease by the medical staff. However, adherence, compliance and persistence as well

to the treatment as the chronic disease monitoring depend on good knowledge of the disease by the patient and consideration of constraints, of his feelings and even his understanding or comprehension about both the disease and its treatment [15-17]. This process can only be considered in the context of more effective communication from the medical team. This approach, although it might be time consuming for the medical staff because of the low ratio of doctors / population, in our context, would significantly improve the chronic disease management and prognosis such as sickle cell anemia, despite the limited human, material and financial resources in our countries. The task may be delegated to paramedics in medical services (nursing assistants, nurses, etc.) specially trained to deliver workshops on health education, education for behavior change (IEC) in these services.

### Conclusion

The sickle cell patients ophthalmologic monitoring is the key to prevent blindness and low vision due to sickle cell disease. Given the frequency of the disease in our population, a good level of patient knowledge (health education) about the disease and its complications should be a contributing factor to both the patient's adherence and compliance regarding the monitoring. However, our study showed that this level of knowledge remains average with regard to the general manifestations of sickle cell disease but remains very low with regard to its ocular complications and ways of preventing transmission of the disease. If this low level of knowledge can be explained by a lack of curiosity on the patient side, it is explained, in our study by the insufficiency of the doctor-patient communication both among hematologists and the ophthalmologists. Certainly the lack of qualified human resources and very limited material and financial resources characterizing our health systems don't help. However, poor doctor-patient communication that is causing the poor patients health education regarding chronic diseases such as sickle cell is, in our opinion, a major obstacle to the efficient and effective global management of these diseases. Given the very high workload of medical staff due to low physician / population ratio in our contexts, information and health education task could be delegated to health workers trained for this purpose. These health workers trained on site according to national guidelines, in services in charge of chronic diseases management should deliver health education workshop to the patients in their respective services. It is crucial to keep in mind that even such communication systems and health education should not subtract the doctor of his awareness duty of the patients. The chronic disease prognosis could be improved over the long term through better multidisciplinary team efforts and knowledge sharing. The incidence of blindness and low vision caused by sickle cell disease, certainly underestimated, could then be reduced.

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