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Problematic Access to Care for People with Sickle Cell Disease in Guinea: Case of the SOS DREPANO Center in Conakry

Diakité Mamady[1,2], Bangoura Mariama[1], Condé Abdoulaye[1], Doukouré Aboubacar Sidiki[1,2], Camara Amadou Sekou[1], Diallo Abdoul Goudousy[1,2], Kouyaté Fodé[1], Dambakaté Alhassane[1], Oularé Ansoumane[1], Camara Saidouba Chérif[3], Kanté Ansoumane Sayon[1,2]

[1]Hematology Department of CHU (Centre Hospitalier Universitaire) of Conakry, Conakry, Guinea
[2]Faculty of Health Sciences and Techniques of the Gamal Abdel Nasser University of Conakry, Conakry, Guinea
[3]Center for Research and Information in Infectiology of Guinea (CERFIG), Conakry, Guinea
Email: mamadydiankana@yahoo.fr

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Abstract

Introduction: Sickle cell disease is a hereditary disease associated with a wide range of complications that pose enormous obstacles to care. Dans cette étude, il était question d'évaluater les difficulties d'accessibilité aux soins chez les patients suffering from sickle cell disease in Guinea. **Methods:** This is a transversal study, with a descriptive aim of three (3) months going from December 15, 2023 to March 15, 2024 at the SOS DREPANO Center in Conakry. Our study population consisted of all patients and/or their tutors who received external consultation and/or were hospitalized and responded to our selection criteria, as well as all health providers who consented to the study. **Results:** The study allowed us to determine the types of care received by patients in the critical phase and in the inter-critical phase, but also the different obstacles and limits to health care. Thus, financial accessibility, access to medicines, the cost of medical services, administrative barriers, the knowledge and attitudes of providers, the lack of medical equipment, the obstacles linked to the disease and the person... were so many obstacles reported by our respondents. **Conclusion:** Sickle cell patients faced countless obstacles to receiving health care that it was urgent to identify in order to improve their care.

Keywords

Sickle Cell Disease, Soins, Accessibility, Difficulty, Guinea

1. Introduction

Sickle cell anemia (SCD), also known as sickle cell anemia, is a hereditary disease

of hemoglobin [1]. It is the result of an autosomal recessive genetic disorder of red blood cells characterized by sickle cell formation, a condition in which the red blood cells take the shape of a croissant or a sickle as opposed to the normal disc shape that is sufficiently flexible to move easily through the blood vessels [2].

Characterized by intermittent vaso-occlusive events and chronic hemolytic anemia, the vaso-occlusive events of sickle cell disease lead to tissue ischemia leading to acute and chronic pain as well as organic lesions that can affect any organ system, notably the bones, heart, liver, brain, lungs, kidneys and joints [3].

Sickle cell disease is a serious public health problem, present mainly in tropical countries, particularly in sub-Saharan Africa [4]. According to the WHO, close to 5% of the world's population are carriers of a gene responsible for a hemoglobin abnormality and the majority of people with sickle cell disease live in Black Africa with prevalences that vary between 10 and 40% [5].

In Guinea, in 2019, Camara E *et al.* they found 7.8% of major sickle cell syndrome (SDM), although it does not represent the national level [6].

There are 5 to 20% carriers of the disease in West Africa (Senegal: 15%, Togo: 16%, Ivory Coast: 12%) and up to 40% in certain ethnic groups in Central Africa (Cameroon: 10 to 25%, Zaire: 20 to 40%, Gabon: 24%) [7].

The complications of sickle cell disease are numerous and include intense pain called vaso-occlusive crisis (CVO), acute chest syndrome and cerebrovascular accidents (AVC) [8]. The treatment of complications, associated with prevention therapies has significantly improved the life expectancy of patients living with sickle cell disease, with more than 93% of children surviving to adulthood [9].

Despite the complexity and importance of the care required by patients suffering from SCD, many obstacles such as administrative barriers, the cost of treatments and the knowledge and attitudes of health providers prevent equitable access to health care [8].

In high-income countries, the therapeutic success of people with sickle cell disease depends on the fact that they receive timely medical care, including quality follow-up based on the early diagnosis of complications and WHO recommendations for treatment (penicillotherapy, folic acid supplementation), disease-specific therapeutic education, psychosocial care and genetic counseling [10].

Disparities in the supply of health care have been widely discussed in the literature, putting more light on the inequalities in access to health care throughout the world, but it is essential to emphasize that they are not specifically focused on the obstacles linked to the reception of care specific to sickle cell disease [9] [11].

In Guinea, few studies have looked at the issue of receiving sickle cell care; for example, it appears that it is opportune to realize this work which, if it proves to be effective, will allow for reflections for the amelioration of the care for sickle cell disease patients in Guinea.

Objective of the study

Evaluating the obstacles linked to the accessibility of care in patients with sickle cell disease in Guinea.

Specific objectives

- Describe the types of care received by sickle cell patients.
- To determine the difficulties in accessing care for patients with sickle cell disease.
- Identify the limits of taking charge of sickle cell patients.

2. Materials and Methods

Type of study

The study was conducted in the city of Conakry.

The center of charge of sickle cell patients (SOS-Drépano) served us as a framework for the realization of this work.

Sampling

➢ For service providers

Nous avons proceeded to an exhaustive recruitment of the ensemble of care providers involved in the care of sickle cell disease.

➢ For sickle cell patients

To calculate the sample size, we used the SCHWARTZ formula.

$$n = P\ (1 - P) * Z2/i2$$

where

n: is the size of the calculated sample

Q: is the prevalence, estimated proportion of the population that represents the characteristic. In our case, we will take a proportion of 20%.

Z: is the confidence level (the typical value of the 95% confidence level will be 1.96)

and: est la marge d'erreur (generally fixed at 5%).

$$n = 0.2\ (1 - 0.2) \times 1.962/0.05$$

$$n = 246$$

Thus, we have 246 patients to include in this study.

We proceeded to a systematic random sampling which consisted of calculating a sampling step. According to the information received at the level of the registers, on average the center receives 15 to 20 patients per day. Considering that our study will be carried out over a period of three months, we have received the effective number of patients received during the previous three months of our study corresponding to 661 patients, the calculation of the survey step (k) was determined by dividing the number of patients estimated to be consulted by the required sample size.

$$k = n/N * 100$$

$$k = 3$$

The first sample was comprised between 1 and Kth and chosen at random, then we took each Kth participant for the rest. The procedure was repeated until the estimated size of the eligible sample was reached during the study period. In case of refusal to participate, the next participant was approached.

Data collection

The data entered using the Kobocollect application was exported to the R application for processing and analysis.

Data management and analysis

The descriptive analysis of the ensemble of selected variables was carried out. The socio-demographic characteristics of the study subjects were described. The effects and percentages were calculated for each qualitative variable selected and the mean plus or minus the standard deviation for the continuous quantitative variable.

Ethical considerations

Free, oral and informed consent was obtained for each patient and the information received was kept confidential and used only for scientific purposes.

Result

The findings of this study are presented in the following section (Tables 1-3).

Table 1. Socio-demographic characteristics of the respondents.

Features		Staff (N = 166)	Percentage %
Sex	Woman	78	47.0
	Man	88	53.0
	Sex ratio M/F: 1.12		
Age range	1 - 10 years	79	48.0
	Mean: 13.63, Standard deviation: 9.75, Minimum: 1, Maximum: 68		
Profession	Student	126	76.0
Marital status	Married	10	6.0
	Single	156	94.0
Residence	Conakry	134	80.7
	Outside Conakry	32	19.3
Education level	Not educated	23	13.9
	Primary	83	50.0
	Secondary	36	21.7
	Superior	24	14.4
Profession of health providers	Pharmacist	2	5.0
	Doctor	5	25.0
	Laboratory technician	3	15.0
	Nurses	10	55.0

Table 2. Type of care received by patients.

Variables		Staff (N = 166)	Percentage %
Type of care received	Medical care	166	100
Critical phase	Analgesics	140	84.3
Inter-critical phase	Folic acid supplementation	151	90.9

Table 3. Difficulties and limits perceived by patients and health providers.

Variable		Staff (N = 166)	Frequency %
Are you having difficulties with the PEC of your illness?	Yes	141	84.9
	No	25	15.0
If yes, at what level?	Administrative barriers	108	76.6
	Knowledge and attitudes of service providers	49	34.8
	Social, family support	135	95.7
	Individual obstacles	111	78.7
	Obstacles related to illness	133	94.3
	Difficulty finding blood	2	0.7
Are there financial difficulties present in the PEC of your disease?	Yes	152	91.6
	No	14	8.4
If yes, at what level?	High transportation costs	85	55.9
	Cost of medical services	112	73.7
	Access to medicines	149	98.0
Limits perceived by health providers	Lack of medical equipment	20	100

3. Discussion

This was a cross-sectional study of a descriptive type during which we questioned 166 sickle cell patients and tutors of sickle cell children and 20 health providers involved in the care of sickle cell patients on the difficulties and limitations of access to care for patients.

The majority of patients surveyed were children. This study carried out at the SOS DREPANO center in Nongo aimed to determine the obstacles linked to the accessibility of care for sickle cell patients in Guinea, the difficulties encountered were: the language barrier, the short time between the interview and the consultations that did not allow us to ask all our questions to the patients, the state of health of certain patients whom we could not address and the refusal of participation of certain patients and/or their parents and health providers. as a result of these difficulties, we were unable to reach the planned 246 patients after calculation.

The result of our study was that the SS homozygous phenotype was the most common with 153 cases. The same observation was made by Kolié in his study at the Ignace Deen National Hospital, which found 117 cases of SS sickle cell patients, but it remains different from that of Ayéroué J. *et al.* [12] in Ouagadougou who found 62% of SC against 38% of SS. The particularity of Burkina Faso is that the frequency of HbS is less important than that of HbC [12].

More than half of all our patients received ambulatory care because they were not hospitalized, which indicates that the SOS DREPANO center is only a day hospital, so it is impossible to spend the night there and the inpatients (hospital-

ized) cannot stay until 6 p.m.

Our study reported that all our patients received medical care and the critical phase treatment consisted of analgesics, anti-inflammatories and blood transfusions. This result is in some points different from that of Diakité M. *et al.* who reported that patient treatment was essentially based on analgesics (96.04%), hydration (85.15%) and antipyretics (64.36%); while in the inter-critical phase, our patients received folic acid supplementation, antimalarial prophylaxis and penicillotherapy. A study conducted in the Congo by Aloni *et al.* [13] I observed that 98% of patients with sickle cell disease were taking folic acid; by the way, another study conducted by Galadanci *et al.* in Nigeria showed that only 1.5% of sickle cell patients had access to penicillotherapy [14] et Paul *et al.* in Kinshasa report that antimalarial chemoprophylaxis was undertaken by 11.6% of participants [15]. However, although thebacterial resistance to penicillin is increasingly observed, penicillin prophylaxis is still widely recommended for children with homozygous sickle cell disease and there is evidence that it significantly reduces the risk of pneumococcal infection [16] and as far as antimalarial prophylaxis is concerned, it is recommended by the WHO for sickle cell disease patients in swamp endemic areas [17].

Almost all of our patients have admitted to having difficulties with access to care in the management of their disease globally and have also declared to have financial difficulties in the management of their disease. This would indicate the poverty of households that find it more judicious to use their source of income to solve food-related problems, but also in the fact that sickle cell disease is a disease that represents a difficult medical burden to manage.

The difficulty of financial accessibility includes obstacles such as access to medicines, costs of medical services and finally transport. This result is consistent with a study conducted in Guinea that reports that the unavailability of financial means and the high cost of transport lead to the low rate of use of health care services, constituting an obstacle to care [18].

At the organizational and medico-social level, patients reported obstacles on the administrative barriers as well as on the knowledge and attitudes of the providers and respectively, the long wait, the unpractical opening and closing hours of the clinic and finally the dissatisfaction of the patients towards the provider were the most observed difficulties. This result is commented on in the literature by a study conducted in the United States that reports various obstacles linked to sickle cell health structures (35.3%) notably the difficulty in contacting clinics, less practical hours and long waiting times, but it also reports (56%) obstacles linked to the knowledge and attitudes of providers including the inexperience of the health provider and the lack of training in sickle cell care [11].

At the family and interpersonal level, our patients reported obstacles linked to family and social support, as well as the inability to find community support groups and the absence or lack of support from family or friends were the most reported obstacles. In this study conducted by Philips *et al.*, patients reported re-

lated problems, they not having adequate support or inadequate support from the family, friends, parents/tutors or the community, the support systems being "exhausted" and the survey participants most often mentioned the need for help for daily activities as an obstacle to care (44.6%) [11].

The obstacles at the individual level included obstacles specific to the disease and the person. Thus, the lack of knowledge on sickle cell disease was the most reported individual obstacle and the most frequent concern or fear of disease was the most frequent obstacle related to sickle cell disease. This is explained by the fact that the therapeutic education for sickle cell disease exists but is not carried out correctly, but also because sickle cell disease is a disease that psychologically affects the patient, causing anguish and anxiety.

Regarding the perceived limits of taking charge of sickle cell disease by health care providers, all the providers included in our study reported a lack of medical equipment. This can be explained by the fact that Guinean hospitals in general are faced with a shortage of infrastructure but also of medical equipment, which reduces the quality of patient care.

4 Conclusion

In sum, this study shows that there are a multitude of obstacles to the effective reception of care among people with sickle cell disease in Guinea. It would be wise to consider this disease as a health priority and consider actions for better patient care. The setting up of health centers or dedicated and well-equipped care units and the training of care providers should improve the treatment of sickle cell patients.

Conflicts of Interest

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

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