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Determinants of the Ophthalmological Follow-Up of Sickle Cell Patients at the National Center of Research and Care for Sickle Cell Patients in Lome-Togo

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Abstract

Objectives: To assess the factors influencing the ophthalmological follow-up of sickle cell patients in Togo. **Materials and Methods:** The national center of research and care for sickle cell patients (CNRSD) served as study setting. It was a descriptive and analytical study by interview over a three-month period from December 01, 2020 to March 02, 2021. Was included in the study, any patient with sickle cell disease genotype SS or SC, age ≥ 17 years, regularly followed at the CNRSD and having accepted the interview by a survey sheet. Excluded were patients with sickle cell trait genotype AS or AC or with a disability that prevented them from being interviewed. **Results:** Two hundred and fifty (250) patients with sickle cell disease were interviewed. The mean age was 29.1 years ± 11.12 years [17 years; 67 years] and the sex ratio = 0.52. Nine patients over ten (9/10) attended at least secondary school. The jobless represented 25.60% of the total population followed respectively by students and laborers in 20.40% and 16% of cases. Twenty-four percent (24%) of patients were followed up in ophthalmology department. Statistically, there was no significant relationship between level of education (p = 0.4083), occupation (p = 0.6441) and knowledge of the ocular complications of sickle cell disease. Statistically, there was a significant relationship between knowledge of the ocular complications of sickle cell disease and compliance with ophthalmological follow-up (p = 0.0009). **Conclusion:** The knowledge of eye disorders related to sickle cell disease by patients with sickle cell disease im-

proves their ophthalmological follow-up. Greater awareness on eye disorders related to sickle cell disease by medical staff towards patients with sickle cell disease would improve ophthalmological follow-up.

Keywords

Ophthalmological Follow-Up, Sickle Cell Patient, Ocular Complications, Lome

1. Introduction

Sickle cell disease (SCD) is a qualitative genetic abnormality of hemoglobin, resulting in the formation of hemoglobin "S", which essential property is gelation, responsible for sickling syndrome. It is the most common genetic disorder worldwide, affecting over 120 million individuals [1]. Awareness of the risk of blindness associated with eye diseases (such as Sickle cell retinopathy) in asymptomatic patients is associated with greater attendance of eye care services [2]. Sickle cell retinopathy is caused by the accumulated damage to the microcirculation of the retina leading to ischemic maculopathy and peripheral occlusions [3] [4]. Ocular complications of SCD, including sickle cell retinopathy (SCR), have been shown to increase with age, generally being more common in adults than children [5] [6]. The impact of awareness on knowledge and beliefs may vary according to demographic indices such as age, gender and socio-economic background [2] [7]. In Togo, SCR is the most frequent chronic ischemic complication of this disease, with a prevalence of 17.25% [8]. Among the means of prevention, raising patients' awareness on the ocular complications of the disease, compliance with ophthalmological follow-up and early management of ocular lesions could play an import. The objective of this study is to assess the factors influencing the ophthalmological follow-up of sickle cell patients in Togo.

2. Materials and Methods

2.1. Study Outline

The national center of research and care for sickle cell patients (CNRSD) provided the setting for the study. The CNRSD is an independent center, under the technical authority of the ministry of health, which ensures adequate and specialized care for people with sickle cell disease. It also strengthens screening, raises awareness of SCD and supports clinical and fundamental research. This was a descriptive and analytical study by interview over a three-month period from December 01, 2020 thru March 02, 2021. All patients with sickle cell disease (genotype SS or SC), aged ≥ 17 years, regularly followed up at the CNRSD and who agreed to be interviewed through a survey sheet were included in the study. Excluded was any patient with a sickle cell trait genotype AS or AC or a disability preventing from being interviewed.

2.2. Data Collection and Analysis

Patients were recruited using non-random, exhaustive sampling by interview through a survey sheet. All patients present during the survey period were invited to participate in the survey, taking into account the study's inclusion and exclusion criteria, but also respecting the barrier measures against Covid-19.

The parameters studied were:

- Socio-demographic: age, sex, occupation, level of education.
- Genotype, ophthalmological follow-up of patients.
- Correlation between the ophthalmological follow-up and knowledge of ocular complications related to sickle cell disease.
- Correlation between the level of education, the occupation and the knowledge of ocular complications.

Data were entered into a database designed with Epi data software version 3.1. The descriptive and comparative statistical analysis of the population was performed using R Studio software version 3.4.3. For the comparative analysis, the statistical tests used were Fisher and Chi2 for the comparison of 2 categorical variables. A p value < 0.05 was statistically significant.

2.3. Ethical Considerations

The survey was conducted after obtaining an authorization from the Director of the CNRSD. The study was carried out in compliance with ethical principles as stated in the Declaration of Helsinki.

3. Results

Two hundred and fifty sickle cell patients were interviewed including 55.60% with SS genotype and 44.40% with SC genotype.

3.1. Socio-Demographics

3.1.1. Age and Sex

The mean age was 29.1 ± 11.12 years [17 years; 67 years] and the most represented age range was 20 to 30 years with a rate of 36%. Men represented 34.4% of the population and women 65.6%, *i.e.* a sex ratio of 0.52 (Figure 1).

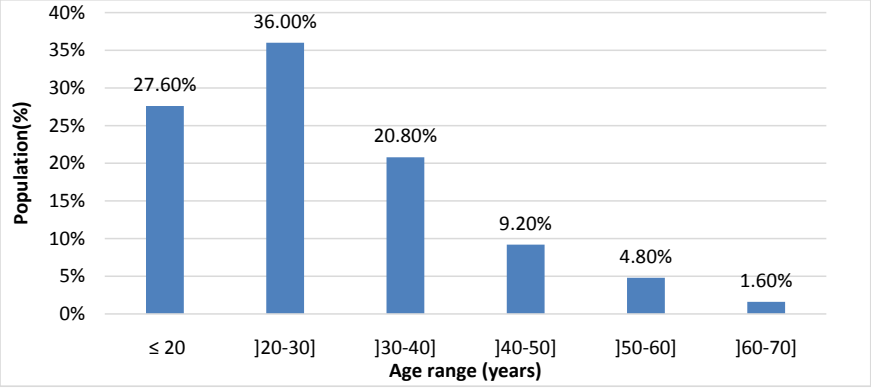

Figure 1. Patient distribution by age.

3.1.2. Level of Education

Nine patients over ten (9/10) attended at least secondary school (Table 1).

3.1.3. Occupation

The jobless represented 25.60% of the total population followed respectively by students and laborers in 20.40% and 16% of cases (Table 2).

3.2. Clinic

3.2.1. The Ophthalmological Follow-Up

Eighty-three point twenty five percent (83.25%) of patients said that ophthalmological follow-up was necessary for sickle cell patients, but only 24% of patients received that follow-up. For those who did, the circumstances that prompted follow-up were medical advice (56.67%) and ocular symptoms (41.67%). The main ocular symptoms were reduced visual acuity (RVA) in 52%, followed by ocular pain in 28% of cases. The frequency of ophthalmological follow-up for sickle cell disease was ≤6 months for 33.17% of SS homozygotes and 30.77% of SC heterozygotes.

3.2.2. Level of Education and Knowledge of Ocular Complications Related to Sickle Cell Disease

Statistically, there was no significant relationship between the level of education and the knowledge about ocular complications related to sickle cell disease ($p = 0.4083$) (see Table 3).

Table 1. Patient distribution by level of education.

	Population	Frequency (%)
Illiterate	04	1.60
Primary	19	7.60
Secondary	116	46.40
Higher studies	111	44.40
Total	250	100.00

Table 2. Patient distribution by occupation.

	Population	Frequency (%)
Student	51	20.40
Laborer	40	16.00
Artisan	39	15.60
Civil servant	22	08.80
Merchant	32	12.80
Retiree	2	0.80
Jobless	64	25.60
Total	250	100.00

Table 3. Correlation between the knowledge of ocular complications related to sickle cell disease and the patients' level of education.

	Knowledge (N = 179)		Lack of knowledge (N = 71)		p value
	n	%	n	%	
Illiterate	2	1.12	2	2.82	0.4083[a]
Primary	14	7.82	5	7.04	
Secondary	79	44.13	37	52.11	
Higher studies	84	46.93	27	38.03	

a = Fisher's exact test.

3.2.3. Occupation and Knowledge of Ocular Complications Related to Sickle Cell Disease

Statistically, there was no relationship between the occupation and the knowledge about the ocular complications related to sickle cell disease (p = 0.6441) (see **Table 4**).

3.2.4. Compliance with the Ophthalmological Follow-Up and Knowledge of Ocular Complications Related to Sickle Cell Disease by the Patient

Statistically, there was a significant relationship between the knowledge of ocular complications related to sickle cell disease and the compliance with the ophthalmological follow-up (**Table 5**).

4. Discussion

Fifty-five point sixty percent (55.60%) of patients had the SS genotype and 44.40% had the SC genotype. We explain this predominance of patients suffering from the homozygous SS form in our survey by the fact that the latter, being responsible for severe anemia with infarction and multiple superinfections [9], would motivate more consultations; unlike the heterozygote SC form, which is less disabling with less severe systemic manifestations. However, it should be noted that the heterozygote SC form is responsible for more frequent retinal manifestations, which slow and sometimes asymptomatic evolution can lead to delayed consultations.

4.1. Socio-Demographic

The mean age of sickle cell patients was 29.1 ± 11.12 years. Our results are similar to those found by Digbe *et al.* with mean age of 28.12 years [10]. The mean age was slightly higher than that in previous studies of the sickle cell population in Ouagadougou and Lome, respectively 26.7 years and 26.92 years [11] [12]. However, these results may reflect the extreme youthfulness of the Togolese population, as demonstrated by the fourth general census of population and houses in Togo in 2010 (RGPH 4) [13]. A female predominance was noticed in the study, with a sex ratio of 0.52. This female predominance is also found in

Table 4. Correlation between the knowledge of ocular complications related to sickle cell disease and the occupation.

	Knowledge (N = 179)		Lack of knowledge (N = 71)		p value
	N	%	n	%	
Student	35	19.55	16	22.54	
Laborers	29	16.20	11	15.49	
Artisan	28	15.64	11	15.49	
Civil servant	19	10.65	3	4.23	0.6441[a]
Merchant	24	13.41	8	11.27	
Retiree	1	0.56	1	1.41	
Jobless	43	24.02	21	29.58	

a = Fisher's exact test.

Table 5. Correlation between the knowledge of ocular complications related to sickle cell disease and the compliance with the ophthalmological follow-up.

	Knowledge (N = 179)		Lack of knowledge (N = 71)		p value
	n	%	n	%	
Followed-up	53	29.61	7	9.56	0.0009[b]
Not followed-up	126	70.39	64	90.14	

b = Chi squared test.

other studies on SCD [8] [14]. On the other hand, a study carried out in Bouake in a sickle cell population revealed a male predominance [10]. This clearly explains why gender is not a factor associated with sickle cell disease.

Secondary and higher levels of education were the most represented, with rates of 46.40% and 44.40% respectively. The predominance of patients with secondary education was also found in the study carried out by Mowatt *et al.* where 61% of patients attended secondary education, while 25% attended higher education [15].

4.2. Clinic

Among the 83.20% of patients who stated that ophthalmological follow-up was necessary for sickle cell patients, 24% had regular ophthalmological follow-up. The rate of patients with regular ophthalmological follow-up is close to that found in the study by Mowatt *et al.* (25%) [15]. We link this situation to the financial difficulties to which sickle cell patients may be exposed when faced with the costs of various ophthalmological check-ups. In addition to financial difficulties, some patients stated "ophthalmological follow-up would be easier for us to observe if ophthalmology services were close or directly attached to our follow-up center".

Statistically, there was no significant relationship between the level of educa-

tion and the knowledge about ocular complications related to sickle cell disease (p value = 0.4083). Our results are similar to those of Cheucheu *et al.* (p = 0.077) [16]. We believe that a high level of education is a factor that favors the assimilation of information given by medical staff. The lack of association between level of education and knowledge of the ocular complications related to sickle cell disease could be explained by a lack of involvement of patients in their ophthalmological care due to a lack of awareness about SCD.

Occupation is the means of obtaining social income; and it is through that patients can pay for the check-ups included in ophthalmological follow-up and thus continue the follow-up through which they acquire knowledge about the ocular complications related to the disease. Statistically, the correlation between knowledge of the ocular complications related to sickle cell disease and occupation showed no significant relationship between the two parameters (p = 0.6441). The same result was found in a study carried out in 2004 by Guédéhoussou *et al.* [14] where occupation had no influence on the level of knowledge about complications related to SCD (p = 0.79). It is therefore important to take into account the professional difficulties of sickle-cell patients and the impact of this disease on social income, which is an important factor for the compliance with ophthalmological follow-up. According to a study by Tchikaya *et al.* [17], SCD is a disease which complications have a major impact on professional activity. According to the analysis in this study, 24.40% of employees benefited from arrangements: 2.40% from job adaptation and 22% from workload reduction. Two point forty percent (2.40%) of job reclassification and job loss were reported following unfitness for work [17]. Statistically, a significant association was found between patients' knowledge of eye disorders related to sickle cell disease and their compliance with ophthalmological follow-up (p = 0.0009). This suggests that compliance with ophthalmological follow-up depends on sickle cell patients' knowledge about the eye disorders related to sickle cell disease.

5. Limitations of the Study

The main limitation is that of a qualitative interview study, since the information given by patients may be influenced by the interviewer or the people around them. In addition, the study is monocentric, which limits the generalizability of the results to the whole country.

6. Conclusion

Sickle cell retinopathy, especially proliferative retinopathy, is the most serious ocular complication of sickle cell disease. Ophthalmological follow-up of sickle cell patients has been irregular, whatever their occupation or level of education. The knowledge of sickle cell patients about the eye disorders related to sickle cell disease improves their ophthalmological follow-up. Greater awareness about eye disorders among the population in general and sickle cell patients in particular by medical staff will improve ophthalmological follow-up and lead to a reduction in the prevalence of blindness due to sickle cell disease.

Conflicts of Interest

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

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Survey Sheet

I. Socio-demographic data

1. Age: .....
2. Sex:
   Male☐ Female☐
3. Ethnicity:
   Ewe☐ Kabyè☐ Kotokoli☐ Autres:_____
4. Educational level:
   Illiterate☐ Primary☐ Secondary☐ High school☐ University☐
5. Profession:
   Student☐ Workers☐ Craftsmen ☐ Farmers ☐ Civil servant☐
   Shopkeeper☐ Retired ☐ Unemployed ☐ Autres:_____
6. Marital status:
   Single☐ Married ☐ Divorced ☐ Widowed ☐
7. Place of residence:
   Urban☐ Rural☐
8. Religion:
   Christian ☐ Muslim ☐ Animist ☐ Other: _____

II. Clinical data

9. Sickle cell genotype:
   SS☐ SC☐
10. Sickle cell follow-up:
    Yes☐ No☐
11. If Yes, Follow-up center: _____
12. Year follow-up began: _____
13. Number of consultations to date: _____
14. Age of sickle cell diagnosis (in years): _____

III. Knowledge of eye disorders

15. Sickle cell disease is complicated by ocular damage:
    Yes☐ No☐
16. If Yes, source of information:
    Physician (Ophthalmologist)☐ Physician (Hematologist)☐
    Media ☐ Surroundings☐ Other: _____
17. Known sickle cell eye disorders:
    Retinal☐ Non-retinal☐ Nervous☐ Don't know☐
18. Most serious eye damage:
    Retinal☐ Non-retinal☐ Nervous☐ Don't know☐
19. Have you ever heard of sickle cell retinopathy?:
    Yes☐ No☐
20. If Yes, source of information:
    Doctor (Ophthalmologist)☐ Literature☐ Physician (Hematologist)☐
    Media☐ Surroundings☐ Other: _____
21. Factors associated with sickle cell retinopathy:

Age☐ Sex☐ Race☐ Genotype☐ Don't know☐

22. Sickle cell genotype more affected:

Genotype SS☐ Genotype SC☐ Don't know☐

23. Known forms of sickle cell retinopathy:

Proliferative form☐ Non-proliferative form☐ Don't know☐

24. Most severe form of sickle cell retinopathy:

Proliferative form☐ Non-proliferative form☐ Don't know☐

25. Sickle cell retinopathy is a cause of decreased visual acuity.

Yes ☐ No ☐

26. Sickle cell retinopathy causes blindness:

Yes☐ No☐

27. Possible prevention of blindness by:

Early diagnosis of retinopathy☐ Early treatment of retinopathy☐

Sickle-cell follow-up☐ Don't know☐

28. Possible treatment of sickle cell retinopathy:

Yes☐ No☐

29. If Yes, known means of treating sickle cell retinopathy:

Photocoagulation☐ Eye surgery☐

Other: _____ Don't know☐

30. Need for ophthalmological follow-up:

Yes☐ No☐

31. If Yes, frequency of ophthalmological follow-up:

SS: 6 months☐ 1year☐ 2 years☐ Other: _____

SC: 6 months☐ 1year☐ 2 years☐ Others: _____

IV. Ophthalmological data

32. Ophthalmological follow-up:

Yes☐ No☐

33. Circumstances prompting ophthalmological consultation:

Medical advice☐ Ocular symptoms☐ Surroundings☐

Other: _____

34. If ocular symptoms, which ones?

Decreased visual acuity☐ Eye pain☐

Conjunctival jaundice☐ Other: _____

35. Number of ophthalmological follow-ups/year: _____