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Knowledge and Practices of Health Providers on the Diagnosis and Biological Monitoring of Sickle Cell Disease in the City of Kindu, in the East of the Democratic Republic of Congo

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Abstract

Introduction: The diagnosis of sickle cell disease is clinical and biological. It is possible to reduce the morbidity and mortality linked to sickle cell disease thanks to regular clinical and biological monitoring. The objective of this study is to determine the level of knowledge and practices of health providers on the biological diagnosis and biological monitoring of homozygous sickle cell disease in the city of Kindu. **Methodology:** This is a cross-sectional descriptive study carried out between June 04, 2018 and July 28, 2108 with 45 health providers in three structures in the town of Kindu chosen on the basis of a multistage survey. **Result:** The study showed that the level of knowledge of those surveyed about sickle cell diagnostic tests as well as that of follow-up sickle cell disease biological tests was considered to be poor. In 68.8% of cases, the respondents in this study recognize that there is no formal unit specializing in the follow-up of sickle cell children within their respective structures and that 53.3% of them do not have prescribed the search for sickle cell anemia by screening in the prenuptial assessment against only 6.7%. **Conclusion:** This study shows that there are shortcomings in the diagnosis and monitoring of sickle cell children in the city of Kindu. The role of the doctor, the nurse and the laboratory technician is fundamental in both primary and secondary prevention of sickle cell anemia.

Subject Areas

Hematology

Keywords

Sickle Cell Anemia, Knowledge, Practices, Diagnosis, Biological Monitoring

1. Introduction

Sickle cell anemia is a genetic, mono-mutational disease with autosomal recessive transmission, linked to an abnormality in the structure of hemoglobin which leads to the formation of hemoglobin S. It causes 3 main types of manifestations: vaso-occlusive crises, hemolysis chronic with anemia, and increased susceptibility to infections [1]. Sickle cell anemia globally affects 20 - 25 million people, including 12 to 15 million in Africa, 50% to 80% of homozygous sickle cell children in Africa die before the age of 5 [2]. Thus, the United Nations (UN) has recognized sickle cell disease as a global public health problem in terms of mortality, morbidity and significant socio-economic impact associated with the disease [3]. In parts of sub-Saharan Africa, homozygous sickle cell disease affects up to 2% of newborns. More generally, the prevalence of sickle cell trait reaches 10% to 40% in equatorial Africa, 1% to 2% on the coast of North Africa and less than 1% in South Africa. This prevalence in sub-Saharan countries is particularly high in regions where malaria is endemic [4]. The Democratic Republic of Congo (DRC) is the third most affected country in the world by sickle cell disease after India and Nigeria. It is estimated that 25% to 30% of the population are carriers of the sickle cell gene and can transmit tare to their children and that 2% of children are born sickle cell annually in the country [5].

According to the World Health Organization (WHO), 70% of deaths linked to homozygous sickle cell disease can be avoided if early neonatal screening is systematically practiced, which will be followed up by regular monitoring. This has three components, namely follow-up in consultation, therapeutic education and psychosocial care [4].

Sickle cell disease is no longer a disease exclusively followed by specialists in tropical pathology. Any practitioner, whatever their specialty, may have to follow a patient with sickle cell disease [6]. The diagnosis of homozygous sickle cell disease is biological and clinical; during its asymptomatic phase (before 5 to 6 months of birth), only biology allows the diagnosis of the disease. Several laboratory tests are used either to orient or confirm sickle cell anemia. Among the orientation tests we cite the Emmel Test and the Itano Test; and among the confirmatory tests we have phenotypic methods and genotypic (molecular) methods. Phenotypic methods are dominated by hemoglobin electrophoresis with all its variants (electrophoresis on cellulose acetate, agarose gel electrophoresis, capillary electrophoresis, …), by chromatography (with its variants) as well as by

spectrophotometry in mass. All these methods have as a limit the blood transfusion carried out in the three months before the study of the hemoglobinic status. Only molecular tests allow the diagnosis of sickle cell anemia to be made independently of the time of transfusion [7].

The follow-up consultation is summarized by vaccinations, anti-pneumococcal antibiotic prophylaxis, to make the first biological assessment and to establish a medical file and a notebook (notebook) of follow-up. The initial biological assessment focuses on the following analyzes: Hemogram, reticulocyte count, rhesus blood group with extended phenotype, Glucose-6-Phospho-Dehydrogenase (G6PD) assay, serum iron, ferritin and capacity assay total transferrin fixation.

Annually, the following biological examinations must be carried out: Hemogram, reticulocyte count, determination of serum iron, ferritin and total transferrin binding capacity, determination of fetal hemoglobin, calcemia, phosphoremia, blood ionogram, assessment hepatic (transaminases, Gamma Glutammyl Transferase, total and conjugated bilirubin), micro albuminuria; the serology of Parvovirus B19, assay of anti-hepatitis B virus surface antigen (ani-HBsAg) antibodies, search for irregular agglutinins, search for infection with human immunodeficiency virus (HIV) and that to viral hepatitis C virus (HCV) in polytransfused children [8].

In Kindu (Maniema), there is no local branch of the National Sickle Cell Control Program (PNLCD), so that sickle cell control activities are not coordinated. No on-the-job training in sickle cell disease is organized for the benefit of Kindu health providers. In addition to this handicap, there is also the increased lack of equipment and laboratory inputs for the various sickle cell follow-up assessments [9].

According to the latest statistics from the human resources office of the provincial health division of Maniema (DPS), the city of Kindu suffers from a shortage of medical specialists and has only 12 in 6 clinical specialties, namely 3 Gynecologists-obstetricians, 3 Internists, 1 Surgeon, 1 Stomatologist, 2 Pediatricians, 1 Doctor Biologist and 1 Ophthalmologist [10]. Thus, general practitioners, nurses and Biotechnologists are at the forefront in the management of sickle cell anemia by playing a key role in it.

The objective of this work is to determine the level of knowledge and practices of health providers on the diagnosis and biological monitoring of homozygous sickle cell disease in the city of Kindu.

2. Methodology

This is a descriptive, sectional study carried out between June 04, 2018 and July 29, 2018. The population studied was made up of doctors, nurses and medical biotechnologists working in three structures in the town of Kindu, one of which is located in each municipality. We used multistage sampling: the town of Kindu was divided into three clusters (communes), which were all taken. In each commune, a list of health facilities with the three categories of providers was es-

tablished; three pots corresponding to the three communes were created and each containing paper balls. The name of the structure was written on each paper. A draw was carried out to obtain three structures to investigate. In each structure, 5 providers per category were randomly selected. The questionnaires were hand delivered to the respondents, who returned them to us 1 hour later. A total of forty five questionnaires were given to providers.

The questionnaire was established by a team from the Lumbulumbu Hospital Center and validated by a pilot study on 8 healthcare providers including 3 doctors, 4 nurses and 1 Biotechnologist. The questionnaire consisted of open-ended questions, extended over 2 double-sided pages and was made anonymously with information on the provider filling it. The first part of the questionnaire concerned the characteristics of the service provider: name of the structure, profession, sex, age and the second part concerned the actual questions of our evaluation, namely: the capacity of the laboratory of the structure to ask the confirmation diagnosis of sickle cell anemia, the provider's knowledge of biological tests to confirm the diagnosis of sickle cell anemia, the existence within the structure of a formal unit responsible for monitoring sickle cell children, the provider's knowledge of examinations biological monitoring of sickle cell anemia, the search for sickle cell anemia (homozygous and heterozygous) in the prenuptial assessment; the investigation was carried out by the principal investigator.

The level of Knowledge of each respondent on the biological tests for the diagnosis of sickle cell anemia was considered satisfactory, when the interviewee answered one of the following possibilities:

- Hemoglobin electrophoresis,
- Chromatography,
- Mass spectrophotometry,
- Molecular Biology tests.

The level of Knowledge of each respondent on the sickle cell biological follow-up examinations was deemed satisfactory, when the interviewee correctly cited the first three assessments (in bold) from the list below to which he could add others:

- Hemogram coupled to the reticulocyte count
- Determination of fetal hemoglobin
- C reactive protein
- Martial assessment
- Micro-albuminuria
- Parvovirus B19 serology (in the transfused)
- HIV serology (in the transfused)
- Serology for viral hepatitis B and C (in the transfused)
- Search for irregular agglutinins (in the transfused)

Thus, the level of knowledge of all the respondents was judged:

- Excellent if > 80% of the respondents had a satisfactory level of knowledge;
- Good if 60% to 79% of the respondents had a satisfactory level of knowledge;

- Fairly good if 40% to 59% of respondents had a satisfactory level of knowledge;
- Poor if less than 40% of the respondents had a satisfactory level of knowledge.

The study protocol developed was submitted to the Ethics Committee of the Kinshasa School of Public Health and had obtained approval under the number: ESP/CE/132/2018. The investigation obtained also authorization from the Maniema DPS before it took place. The inclusion of the subjects surveyed was subject to agreement by signing the informed consent form.

The data have been grouped in the frequency tables. All of the statistical analyzes were carried out using the Microsoft Excel corporation 2010. The qualitative variables were described in terms of number and percentage.

3. Result

3.1. Socio-Demographic Characteristics of the Respondents

A total of 45 survey sheets from healthcare providers in 3 structures in the town of Kindu were collected. The sex ratio M/F was 1.6; the average age of the respondents was 36.5 years, the youngest was 21 and the oldest was 55.

Of the 45 subjects surveyed, 15 (33.3%) were general practitioners, 10 (22.2%) graduate biotechnologists, 6 (13.3%) level A1 nurses, 5 (11.1%) related biotechnologists, 4 (8.9%) nurses at level A0, 3 (6.7%) nurses at level A2, 2 (4.4%) nurses at level A3.

3.2. Ability of the Laboratory of the Structure Investigated to Make the Confirmation Diagnosis of Sickle Cell Anemia

Of the three structures surveyed, 1 (33.3%) has the capacity to make the confirmation diagnosis of sickle cell anemia thanks to the electrophoresis chain having the possibility of using both the agarose gel and the membrane d cellulose acetate as a support.

3.3. Level of Knowledge of Diagnostic Tests for Sickle Cell Anemia

The level of knowledge of respondents on diagnostic tests for sickle cell disease was poor because only 19.9% of our respondents cited hemoglobin electrophoresis alone or in combination with either the Drepatest® rapid screening test (RDT) or the test of Emmel as diagnostic tests for sickle cell anemia. The study showed that almost half of our respondents (48.8%) knew that only the Emmel test is the means for the biological diagnosis of sickle cell anemia (Table 1).

3.4. Organization of Follow-Up of Sickle Cell Children

In 68.8% of cases, the respondents to this study recognized that there is no formal unit specializing in the follow-up of sickle cell children within their respective structures (Table 1).

Table 1. Diagnostic tests for sickle cell anemia, Organization of follow-up of sickle cell children, Knowledge of biological tests to monitor sickle cell children, Search for sickle cell disease (homozygous and heterozygous) in the prenuptial assessment.

Parameters evaluated	Effectif (n = 45)	%
Diagnostics tests for Sickel cell anemia		
Hemoglobin electrophoresis	12	26.6
Hemoglobin electrophoresis + RDT* Drepatest	2	4.4
Blood count + Emmel test + Hemoglobin electrophoresis	1	2.2
Emmel test	22	48.8
Emmel test + Hemoglobin electrophoresis	6	13.3
Emmel test + RDT Drepatest	2	4.4
Organisation of monitoring for sickle cell children		
Yes	31	68.8
No	14	31.2
Knowledge of follow-up biological examinations of sickle cell children		
Hemoglobin assay	11	24.4
Fetal Hemoglobin assay, White blood cell count, leukocyte formula	2	4.4
White blood cell count, sedimentation rate, Hemoglobin assay	2	4.4
Red blood cell count, White blood cell count, Hemoglobin assay	2	4.4
Blood cell count	7	15.6
Blood cell count + C-Protein reactive	3	6.7
Blood cell count, urea, creatinine, sedimentation rate	2	4.4
Blood cell count, urea, creatinine, research of malaria by tick drop, reticulocyte count, transaminase	2	4.4
Blood cell count, urea, creatinine, reticulocyte count, transaminase, HCV**, AgHBs***	2	4.4
hematocrit	3	6.7
Emmel test	9	20
Search for sickle cell anemia (*homozygous and heterozygous*) *in the prenuptial assessment*		
Never	24	53.3
Sometimes	18	40.0
Always	3	6.7

RDT*: Rapid diagnostic test; HCV**: testing for hepatitis C virus infection de l'infection; AgHBs***: testing for hepatitis B virus infection de l'infection.

3.5. Level of Knowledge of the Follow-Up Biological Examinations of Sickle Cell Children

In general, the level of knowledge of respondents on the follow-up biological examinations of sickle cell patients was poor because only 8.8% of our respondents cited laboratory examinations useful for the biological follow-up of sickle cell children (Table 1).

3.6. Search for Sickle Cell Anemia (Homozygous and Heterozygous) in the Prenuptial Assessment

Among the respondents, 53.3% of them never prescribed the search for sickle cell anemia by screening in the prenuptial assessment against only 6.7% (Table 1).

4. Discussion

Level of knowledge of sickle cell disease diagnostic tests In our study, we showed that the level of knowledge of our respondents on sickle cell disease diagnostic tests was poor because only the Emmel test was used as a diagnostic tool. This finding could be due to lack of on-the-job training on sickle cell anemia. This is a disturbing reality with regard to the primaryprevention of sickle cell anemia. This observation was also made in Lomé by T. Guédéhoussou: for his study, the biological diagnosis of sickle cell anemia was poorly understood due to lack of information [6]. According to the French Society of Clinical Biology, two to three tests of different principles must be done to confirm the diagnosis of sickle cell anemia [11]. Organization of follow-up of sickle cell children More than half of the interviewees in our study acknowledged the absence of a structure or unit responsible for monitoring sickle cell children in the town of Kindu. This evidence is only the corollary of the absence on the ground of the Congolese State in the organization of the fight against the disease within the province of Maniema.

In a study conducted in Gabon between December 2015 and December 2016, Minoto'o Rogombé *et al.*, found that in their sample, almost 1 in 3 subjects had no medical follow-up. This result shows that in Gabon, medical monitoring of sickle cell children is organized. As sickle cell disease is a chronic condition, its management in our context is essentially based on the prevention of acute or chronic complications. This prevention can only be effective if it is based on regular monitoring of the sickle cell subject, allowing therapeutic and clinical monitoring [12].

In the town of Kindu, there is no initiative, either state or private, which organizes the care of sickle cell children. And even non-profit associations do not integrate this aspect of health into Maniema. Level of knowledge of the follow-up biological examinations of sickle cell children In general, the providers surveyed did not correctly quote the follow-up sickle cell biological tests. Their level of knowledge was therefore considered to be poor. For Kitenge R *et al.*, sickle cell anemia being a disease whose complications can interest all systems and organs,

good follow-up requires some tools for monitoring and preventing certain complications. In the context of developing countries, these authors insist in particular on the value of a complete blood count, the martial assessment, the search for microalbuminuria, the search for irregular antibodies, the search for infection with the l virus. hepatitis B and hepatitis C and enlarged blood grouping in polytransfused sickle cell patients [13]. Knowledge of sickle cell anemia should not only remain the prerogative of specialists but of any health provider, of any level whatsoever because sickle cell anemia is a reality in Maniema. It is therefore imperative that the health authorities of the province of Maniema get involved for on-the-job training on the monitoring of sickle cell anemia both clinically and biologically. That the faculties of medicine and the medical science institutions that train doctors, nurses and laboratory technicians insist on sickle cell anemia because it is the fruits of their institutions that will be the frontline responders in the fight against this scourge.

Search for sickle cell anemia (homozygous and heterozygous) in the prenuptial assessment The search for sickle cell anemia in its homozygous or heterozygous form in the prenuptial report is not anchored in the habits of the people of Kindu. As a result, health providers have very little demand for premarital screening. This weakness was also noted in Lomé by T. Guédéhoussou: in his series, the need to look for sickle cell anemia by electrophoresis in the prenuptial assessment was known only by 12.4% of the people questioned [6].

The result found in our study would reflect a 1.9% prevalence of homozygous sickle celldisease in newborns found by Lufimbo *et al.* as a result of neonatal screening in nine health facilities in the city of Kindu in 2018 (9). It is therefore an obstacle in the primary prevention against sickle cell anemiain the city of Kindu. In a retrospective neonatal screening study for sickle cell disease conducted in Awka in south-eastern Nigeria from September 01, 2013 to October 27, 2017, Ejiofor OS. *Et al.* found a prevalence of 0.32% of SS [14]. This low prevalence of homozygous sickle cell disease in newborns is the result of systematic screening for sickle cell disease in prenuptial; for example, in Awka, more and more hemoglobin S carriers are marrying partners with the normal hemoglobin AA phenotype.

Our study limit is that of not having described word experience and eduction background of the participants.

5. Conclusion

This study shows that there are shortcomings in the diagnosis and monitoring of sickle cell children in the city of Kindu. The role of the doctor, the nurse and the laboratory technician is fundamental in both primary and secondary prevention of sickle cell anemia, but there are gaps due to the lack of proper knowledge in the field of sickle cell anemia. The lessons received at the medical school and in the institutions of the medical sciences do not seem to us as sufficient given the impact of SS anemia in our environment. It is therefore more urgent that a

branch of the national sickle cell anemiacontrol program be installed in Maniema in order to boost the fight against this scourge. This study is therefore a mirror that allowed us to project many perspectives and areas for improvement.

Contribution of Our Study to Knowledge

- This study provides indicative data on the level of knowledge of providers in the city of Kindu on the biological diagnosis of sickle cell anemia.
- The study also demonstrates the level of knowledge of providers in the town of Kindu on the biological assessments of sickle cell follow-up.

Author Contributions

Professor Dr. Etienne Shindano Mwamba and Dr. Aime Abdala Kingwengwe contributed to the reading, correction and finalization of the manuscript. They brought important criticisms for the improvement of the content and the form, directions and support for the publication. Antoine Lufimbo Katawandja is the main author of the study, from the survey phase, the collection of data and their interpretation until publication. All authors also declare having read and approved the final version of the manuscript.

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Conflicts of Interest

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

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Appedix (Abstract and Keywords in French)

Résumé

Introduction: le diagnostic de la drépanocytose homozygote est clinique et biologique. Il est possible de réduire la morbi-mortalité liée à la drépanocytose grâce à un suivi clinico-biologique régulier. L'objectif de ce travail est de déterminer le niveau de connaissances et les pratiques des prestataires sanitaires sur le diagnostic biologique et suivi biologique de la drépanocytose homozygote dans la ville de Kindu. **Méthodologie:** Il s'agit d'une étude descriptive transversale réalisée entre le 04 juin 2018 et le 28 juillet 2108 auprès de 45 prestataires sanitaires dans trois structures de la ville de Kindu choisis sur base d'un sondage à plusieurs degrés. **Résultat:** l'étude a montré que le niveau de connaissance des enquêtés sur les tests diagnostiques de la drépanocytose de même que celui sur les examens biologiques de suivi des drépanocytaires étaient jugés médiocres. Dans 68.8% de cas, les enquêtés de cette étude reconnaissent qu'il n'existe pas une unité formelle spécialisée dans le suivi des enfants drépanocytaires au sein de leurs structures respectives et que 53.3% d'entre-eux n'ont jamais prescrit la recherche de la drépanocytose par un dépistage dans le bilan prénuptial contre seulement 6.7%. **Conclusion:** cette étude montre qu'il existe des insuffisances dans le diagnostic et le suivi des enfants drépanocytaires dans la ville de Kindu. Le rôle du médecin, de l'infirmier et du technicien de laboratoire est fondamental dans la prévention tant primaire que secondaire de la drépanocytose.

Mots-clés

Drépanocytose, Connaissances, Pratiques, Diagnostic, Suivi Biologique