ORIGINAL RESEARCH ARTICLE

Acceptability of neonatal sickle cell disease screening among parturient women at the Paul Moukambi Regional Hospital in rural Eastern Gabon, Central Africa

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Abstract

Neonatal screening and the effective management of sickle cell disease (SCD) are now well established in urban areas in some sub-Saharan African countries. The high rate of sickle cell trait in Koula-Moutou, Gabon, prompted an assessment of the psycho-clinical context of the introduction of neonatal screening in this rural area in eastern Gabon. Interviews were conducted with 215 women from February to June 2016 in Maternity and Maternal Child Protection services at the Paul Moukambi Regional Hospital Center in Koula-Moutou. Few childbearing women knew about SCD (24%), very few (6%) knew their hemoglobin status and only 30% of parturient women authorized sampling for neonatal SCD screening. Young mothers aged 16-28 years (p=0.018) and those who were educated (p=0.002) were more likely to authorize neonatal blood screening. There was no association between acceptance of blood sampling and knowledge of SCD or the parturient woman's hemoglobin status. The barriers to acceptance for SCD neonatal diagnosis are related to the education and culture rather than the knowledge of this disease. Introduction of diagnosis in rural areas requires a team comprising a psychosocial worker and health workers known to the rural population, to remove inhibitions related to blood collection from newborn infants. *(Afr J Reprod Health 2021; 25[3]: 72-77).*

Keywords: Sickle cell disease, neonatal screening, knowledge, acceptability, Gabon

Résumé

Le dépistage néonatal de la drépanocytose et la prise en charge des drépanocytaires sont bien établis dans les zones urbaines des pays de l'Afrique Subsaharienne. Le taux élevé du trait drépanocytaire à Koula-Moutou (Gabon) a contribué à proposer l'introduction du dépistage néonatal dans cette zone rurale de l'Est Gabonais. Des entretiens ont été conduits auprès de 215 femmes enceintes, entre février et juin 2016, à la maternité et au centre de protection infantile du Centre Hospitalier Régional Paul Moukambi de Koula-Moutou. Peu de parturientes connaissait la drépanocytose (24%), très peu (6%) connaissait leur statut hémoglobinique et seulement 30% des parturientes avaient autorisé le prélèvement sanguin en vue du dépistage néonatal de la drépanocytose. Les jeunes mères âgées de 16-28 ans (p=0,018) et celles scolarisées (p=0,002) étaient plus nombreuses à autoriser le prélèvement sanguin pour le dépistage néonatal. Aucune association n'a été retrouvée entre l'autorisation du prélèvement sanguin du nouveau-né et la connaissance de la drépanocytose par la mère, et non plus avec le statut hémoglobinique de cette dernière. Les barrières contre l'autorisation du diagnostic néonatal de la drépanocytose sont plus liées à la culture et à l'éducation qu'à la connaissance de la maladie. L'introduction du dépistage en zone rurale requiert une équipe comprenant un travailleur psycho-social et des personnels de santé connus par la population rurale, pour lever les inhibitions relatives au prélèvement sanguin des nouveaux-nés. *(Afr J Reprod Health 2021; 25[3]: 72-77).*

Mots-clés: Drépanocytose, depistage neonatal, connaissances, acceptabilité, Gabon

Introduction

Sickle cell anemia is the most common and the most serious form of sickle cell disease (SCD). Its estimated incidence of 305,800 infants in 2010 is predicted to increase to 40,400 newborns in 2050, mostly in sub-Saharan Africa[1]. SCD is a hereditary disease manifesting as severe acute complications in the first months of life, which can lead to more or less serious sequelae and death. It also results in the gradual onset of chronic complications from adolescence affecting and life quality and

expectancy. Data for several African countries (Zambia, Nigeria, Kenya, Ghana, Burkina Faso, Gambia and Senegal) indicate mortality of 50 to 90% due to SCD in children under 5 years[2,3,4].

SCD remains a major public health concern in Gabon. For example, a study of 947 newborns in Libreville found 15.1% of sickle cell trait carriers, 1.8% of Sickle Cell HbSS and 0.1% HbSC[5]. Of 4068 newborns diagnosed at the Laboratory for Sickle Cell Disease in Libreville, 1.33% were homozygous SS, 16% heterozygous AS, 0.73% heterozygous AC, 0.07% homozygous CC and 0.14% SC SCD patients[6]. SCD caused 7.2% of deaths in a 3-year study in a pediatric ward of Owendo University Hospital Center in urban areas[7].

It has been 30 years since a US study showed an improvement in the state of health and living conditions and a decrease in the mortality of sickle cell patients following neonatal screening and management of sickle cell disease from 1979 to 2017[8]. Another study carried out in Jamaica showed the effectiveness of neonatal screening for SCD and its management in reducing mortality in sickle cell children, mainly by reducing bacterial infections and splenic sequestrations[9,10].

In Europe in countries with African immigration (France, Belgium, and England), neonatal screening programs and management of SCD have been in place for about 20 years. In the United States and Canada, neonatal screening and management of SCD were initiated much earlier than in Europe[11]. In sub-Saharan Africa, newborn screening tests for SCD have been initiated in many countries (Nigeria, Benin, Ghana, Kenya, Senegal, Mali, Burkina, DRC, Cameroon, Rwanda, Gabon) but very few countries have a universal screening program (Ghana is an exception)[12]. The beneficial effects of universal screening programs for SCD are a reduction in infant mortality of 8,335,100 lives in sub-Saharan Africa[1]. A study using an analytical decision model analyzed screening for SCD and its management in 47 countries in sub-Saharan Africa and found it highly cost-effective in 24 countries including Gabon[13].

Rural areas are very often disadvantaged in health facilities in sub-Saharan Africa, for both SCD and other diseases. For example, a recent study in a semi-rural area in southwestern Nigeria showed a lack of neonatal screening for SCD[14]. The same is true for Gabon. Despite the establishment of the National Program for the Control of SCD in 2007, neonatal screening for SCD is not universal in Gabon. Neonatal screening is practiced only in urban areas in the Laboratory of Sickle Cell Disease at the Faculty of Medicine of Libreville.

The psycho-clinical conditions of the introduction of adapted neonatal screening in rural areas are the subject of this study. In particular, the knowledge of SCD and the acceptability by the parturient women of blood sampling of their newborns were analyzed.

Methods

The study was conducted at the Paul Moukambi Regional Hospital Center of Koula-Moutou (CHRPM), in eastern Gabon between February and June 2016. CHRPM is the biggest hospital in the Ogooué-Lolo region with a delivery rate of 806 per year. Of the 745 births during the study period, only 215 mothers who accepted to participate were recruited into the study. Each mother was interviewed using a structured questionnaire to determine her hemoglobin phenotype status, her knowledge of SCD and to raise awareness about sickle cell disease with submission of a booklet in easy French. The interview took place a few hours after the birth of the newborn at the maternity ward. The study data was analyzed with Statistical Package for Social Sciences software version 20 (SPSS, IBM corporation, USA). The differences were considered significant for $p < 0.05$.

Results

Of the 215 parturient women enrolled in the study, 84 were unemployed (39%), 54 were students (25%) and 77 were employed (36%). Nearly a quarter of subjects, 52/215 (24%), knew about SCD. However, very few subjects, 14/215 (6%), had had their hemoglobin typed by electrophoresis. Nearly one third of parturient women, 65/215 (30%) agreed to allow blood sampling of their baby for neonatal screening for SCD. Blood sampling of newborns was made only at the request of parturient women in the maternal child protection structure by a nurse at the earliest one month after birth.

Knowledge of SCD and hemoglobin status was not associated with acceptance of neonatal blood sampling by parturient women (Table 1). However, younger ($p = 0.018$) and more educated parturient women ($p = 0.002$) were significantly more likely

Table 1: Relationship between acceptance of neonatal blood sampling, knowledge of SCD, age group and occupational category of parturient women

Characteristics		Acceptance of newborn blood sampling		Statistical tests
		Yes	No	P-value
Knowledge of SCD	Yes	17/52 (33%)	35/52 (67%)	0.864 (Exact Fisher test, OR=1.097)
	No	50/163 (31%)	113/163 (69%)	
Knowledge of Hemoglobin status	Yes	3/14 (21%)	11/14 (79%)	0.557 (Exact Fisher test, OR=0.585)
	No	64/201 (32%)	137/201 (68%)	
Age group	16-28 years	53/145 (37%)	92/145 (63%)	0.018 (Exact Fisher test, OR=2.296)
	29-40 years	14/70 (20%)	56/70 (80%)	
Occupational category of parturient women	Students	25/54 (46%)	29/54 (54%)	0.002 (2 x 3 Table Chi-square test)
	Unemployed	28/84 (33%)	56/84 (67%)	
	Employed	14/77 (18%)	63/77 (82%)	

We counted births per month at CHRPM (Figure 1) to assess the importance of SCD neonatal screening. In 8 months, from January to August 2016, there were 745 births. This is 93 births per month or 3 births per day, with a peak birth rate in June (147 births).

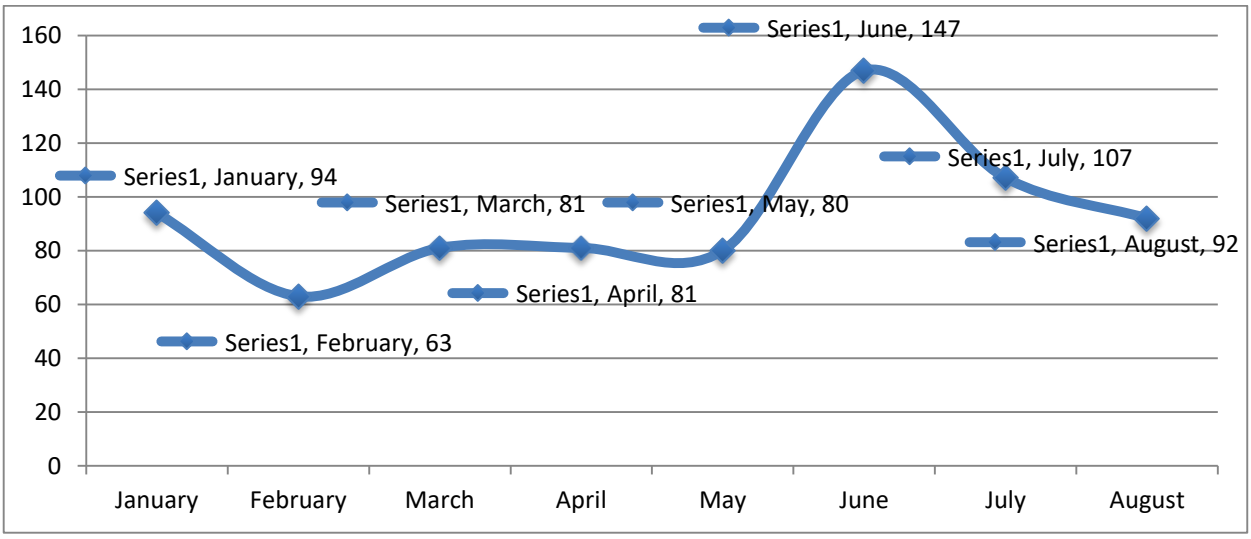

Figure 1: Number of births per month from January to August 2016 at the Paul Moukambi Regional Hospital Center of Koula-Moutou

to accept blood sampling of their newborns. More than three-quarters (79%) of parturient women who authorized blood sampling from their newborns were aged 16-28 years (Table 1). Nearly half of the students (46%) allowed their neonates to be tested for neonatal SCD screening, compared with 26% for other parturient women (Table 1).

Discussion

Knowledge of parturient women

Basic knowledge of SCD in this study (24%) was low compared to other African populations. For example, knowledge of SCD is around 53% in the western regions of Sudan[15]. This can be explained in part by the rural nature of our study population. Information channels are reduced and schools are restricted to middle and high school levels in Koula-Moutou. Parturients' knowledge of SCD is also quite high in the Caribbean islands, with 63.6% knowledge in Saint Lucia[16]. Developed countries such as the United States of America have the highest rates. For example, 96% of subjects knew about SCD in a study conducted at the University of Chicago[17].

Parturient women rarely know their hemoglobin status (6%) in rural areas in Koula-Moutou, in contrast to the populations of urban areas of African countries and developed countries. In the general population of Lome (Togo) in 2004, 22% of individuals (47/210) had had hemoglobin electrophoresis[18]. At the Medical Center of the University of Chicago (USA), 46% of parturient

women said they knew their hemoglobin profile in a study conducted in 2009[19], and 80% of mothers knew their hemoglobin status in another study in 2013[1]. This is partly the consequence of a total lack of genetic counseling in rural areas in Gabon. This is worrying considering that the highest rate of subjects carrying the sickle cell trait in Gabon is found in the region of Koula-Moutou with 28.2%[20].

Acceptance of blood sampling of newborns

In addition to the very high prevalence of sickle cell trait carriers in the study area, the size of the Maternity Service, with an average of 3 births per day, shows the need for universal neonatal screening for SCD in this rural area. Universal neonatal screening for SCD is becoming the rule even in countries with a low prevalence, such as the United States of America, the United Kingdom and Belgium. Universal neonatal screening experiments in some countries, such as France, who have neonatal diagnosis for target populations, have shown their effectiveness[21].

Blood sampling of newborns is a crucial step in neonatal screening for SCD. The acceptance of blood sampling of newborns in rural area in Koula-Moutou, is low (30%) despite the information conveyed during the interviews, and is lower than the acceptance of 54.14% recorded in urban areas in Libreville (Gabon)[5]. The reasons for this low acceptance of the blood sampling are likely to be difficult to change and may come from local beliefs that blood is a sacred product. Blood is a vector of maternal lineage in many African cultures and could be used for occult practices[22].

In addition, as demonstrated in a study in Kenya, mothers are often blamed when newborns are diagnosed with sickle cell disease[23]. In Bantu populations, like the parturient women of this study, traditions are based on a maternal lineage and the child carried by a mother is her responsibility. In some African cultures, for example, blood diseases are considered to be transmitted by the mother[24]. This stigmatization by the extended family can be another barrier for women to accept blood sampling of their newborn for the diagnosis of SCD.

Parental education on the neonatal diagnosis of SCD is an essential tool to improve the acceptance of neonatal blood sampling. For example, prenatal education significantly increases the follow-up rate for infants[25].

In this study, the age of mothers and their level of education were associated with higher acceptance of the neonatal tests for SCD. Younger generations are less anchored in the ancestral customs, which facilitates their acceptance of the neonatal diagnosis of SCD. Neither their knowledge of SCD nor their hemoglobin status led mothers to allow the blood sampling of their newborns. The procedures for fingerpick blood sample collection on filter paper; processing, storage and transportation are standardized and are easily adaptable. Blood sampling is possible only 30 days after birth. Sampling at 4 days is unrealistic in an environment where traditions confine the newborn during a lunar cycle (1 month) before it is presented to the community. A well-known nurse or nursing assistant from the Maternal and Infant Protection Service is the appropriate agent to carry out the entire procedure and send the samples to the Laboratory, which studies hemoglobinopathies.

Conclusion

This study showed that few childbearing women know about SCD and that a large majority of them do not know their hemoglobin status in rural areas. Barriers to the acceptance of neonatal SCD screening are related to people's habits and customs rather than to knowledge of the disease. The establishment of a neonatal SCD screening in rural areas requires a team comprising a psychosocial and health worker familiar to rural people, to address inhibitions related to neonatal blood collection.

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Competing interests

The authors declare that they have no financial or personal relationship(s) that may have inappropriately influenced them in writing this article.

Author contributions

LEM and AE designed the study. LKM and KM collected data. LEM, LKM, CB, KM and AE

analyzed data. LEM, CB and JMS wrote the manuscript. LEM, CB, JMS and AE corrected and approved the final version of the paper. All the authors read and approved the final version of the manuscript.

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