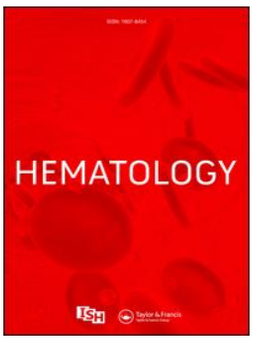

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Students' knowledge on sickle cell disease in Kisangani, Democratic Republic of the Congo

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ABSTRACT

Background: Education is needed as an action to reduce morbidity and mortality from sickle cell disease (SCD), an important but largely neglected risk to child survival in most African countries as Democratic Republic of Congo (DRC).

Objective: To assess the knowledge of Kisangani University students in DRC regarding SCD.

Methods: In this non-experimental, cross-sectional study, a validated questionnaire was used to assess the knowledge of 2 112 Kisangani University students in DRC and data were analyzed using SPSS version 20.

Results: Most participants, 92.9% (95% confidence interval [CI]: 91.7–93.9) were knowledgeable about SCD and have heard about it through schools and/or universities (46.3%), followed by family (34.5%) and health-care workers (23.5%). Nine hundred and seventy-three (46.1%; 95% CI: 44.0–48.2) and 37.9% (95% CI: 35.9–40.0) subjects indicated, respectively, that SCD is an acquired and hereditary disease. Moreover, 53.6% (95% CI: 51.5–55.7) said that the diagnosis of SCD is made by blood tests, while 46.2% (95% CI: 44.1–48.3) talked about urine tests. About 85.6% were unaware of the risk of children becoming sickle cell patients when both parents have SCD. To prevent SCD, pre-marital screening was cited by only 7.7% (95% CI: 6.6–8.9) of subjects and no measure was known by 25.4% (95% CI: 23.6–27.3). However, 79.6% (95% CI: 77.8–81.3) approved the need of pre-marital screening of SCD.

Discussion: This study highlighted that the Kisangani university students' knowledge regarding SCD is poor and needs to be improved; education programs and motivational campaigns to be enhanced.

KEYWORDS
Sickle cell disease; knowledge; students; Kisangani university

Introduction

Sickle cell disease (SCD) is the most common genetic disease worldwide. In 2010, it was estimated that 5,788,000 neonates were affected by HbS including 5,476,000 heterozygous and 312,000 homozygous [1]. In sub-Saharan Africa, SCD affects up to 3% of births in some parts of the continent. However, it remains a low priority for many health ministries. Although the world health organization (WHO) recommends education of the population as a way to reduce mortality from SCD [2], the disease remains little known or unknown by people in sub-Saharan African countries most affected. Indeed, several studies conducted in sub-Saharan Africa on the population's knowledge of SCD had generally reported insufficient or erroneous knowledge of this disease [3–7]. As a result, myths about SCD, frustration, stigmatization and inappropriate treatment persist [4,5,8].

The Democratic Republic of the Congo (DRC) is one of the three most affected countries by SCD worldwide and it is estimated that in 2050, Nigeria and the DRC will remain as the countries most in need of policies for the prevention and management of SCD. [9] However, studies concerning the population's knowledge on SCD are scarce. Nevertheless, some studies in the DRC focusing on knowledge of SCD were carried out in family members of sickle cell patients [7,8]. Thus, it seems appropriate to conduct a survey on the level of knowledge of SCD among educated population such as students. This study aims to evaluate the students' knowledge on SCD in Kisangani, DRC.

Material and methods

This representative cross-sectional study was conducted from January to April 2017, using a self-

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administered semi-structured questionnaire. The survey was conducted at the University of Kisangani which is one of the three largest universities in DRC, with about 10,000 students. Five faculties (Faculty of Arts and Humanities, Faculty of Law, Faculty of Economics and Management, Faculty of Social Sciences Policy and Administrative, and Faculty of Medicine and Pharmacy) were randomly selected from eight faculties of Kisangani's university. From the list of students in alphabetical order for each faculty, systematic random sampling was performed to produce a representative sample of students. The requested minimum number of students to include was estimated at 322 students per faculty. Inclusion criteria were to be regularly enrolled for the academic year 2016–2017 and to have the willingness to provide verbal consent.

The questionnaire was established on the basis of the literature review on the knowledge of SCD [3–6,10–15], then the questionnaire was validated to be used among the students. The study was conducted following STROBE (Strengthening the reporting of observational studies in epidemiology) guidelines for reporting quantitative data [16]. The validated questionnaire contained items on socio-demographic characteristics, knowledge and attitude regarding SCD.

Ethical clearance for this study was obtained from Ethics Committee of the Kisangani's University. All participants gave their verbal informed consent. All data were entered into an Excel file and analyzed on SPSS 20.0 (Chicago, IL). Proportions were calculated for categorical variables; and the results were presented as a 95% confidence interval (CI) using the Wilson score bounds. Missing values were replaced by the single imputation using the regression method.

Results

Out of a total of 2837 students assessed for eligibility, 2112 were enrolled in this study (Figure 1).

Majority (55.2%) of students was male, single (87.6%) and was between 20 and 29 years old (76.7%) (Table 1).

The results of the knowledge assessment are presented in Table 2. Indeed, majority of students (92.9%; 95% CI: 91.7–93.9) were aware of the existence of SCD mostly via school activities (49.8%; 95% CI: 47.7–51.9). Nevertheless, few students (37.9%; 95% CI: 35.9–40.0) indicated that SCD is a hereditary disease. In addition, 53.6% (95% CI: 51.5–55.7) said that the diagnosis of this disease is made by blood tests while 46.2% (95% CI: 44.1–48.3) talked about urine tests. About 85.6% were unaware of the risk of SCD in children when both parents have SCD. To prevent this disease, pre-marital screening was cited by only 7.7% (95% CI: 6.6–8.9) of participants and no measures were known by 25.4% (95% CI: 23.6–27.3) of students. However, 79.6% (95% CI: 77.8–81.3) agreed with the need for pre-marital screening for SCD (Table 3).

Discussion

An effective fight against SCD requires not only a multidisciplinary approach (health personnel, pharmacists, geneticists, psychologists and anthropologists) but also the involvement of the population, an essential partner in the fight. Indeed, ignorance and misperceptions of the population on SCD have been reported as barriers to sickle cell care [7]. They may even influence the acceptability and practice of pre-marital screening for this disease [4].

In this study, which focused mainly on single people (87.6%), future parents, majority aged between 20 and 29 years (76.7%), 92.9% were informed of the existence of SCD (95% CI: 91.7–93.9) with the main sources of information being schools and/or universities (49.8%), families (34.5%) and health-care workers (23.5%). Our result converges with that of Boadu and Addoah in Ghana regarding knowledge about the existence of

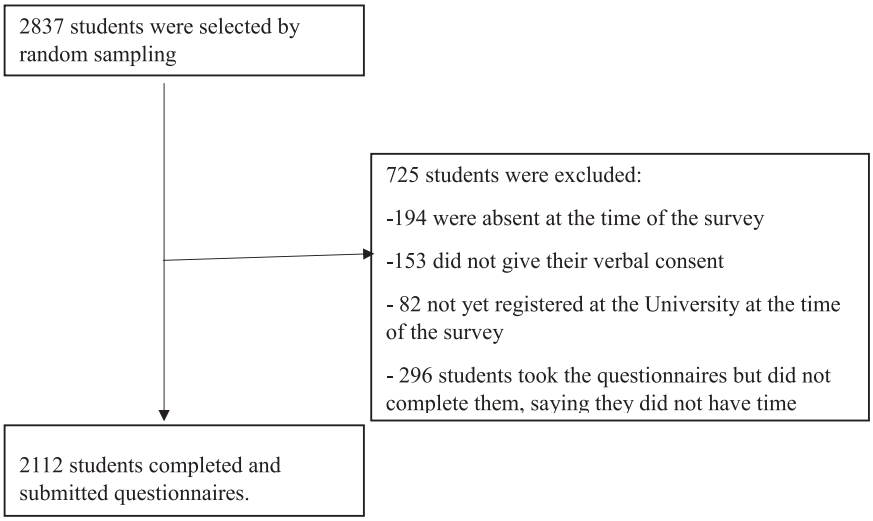

Figure 1. Participants recruitment.

Table 1. Socio-demographic characteristics of 2112 students.

Characteristics	Number (n = 2112)	%
Age (years)		
<20	408	19.3
20–29	1619	76.7
≥30	85	4.0
Sex		
Female	946	44.8
Male	1166	55.2
Marital status		
Single	1851	87.6
Married	154	7.3
Other	107	5.1
Religion		
Christianity	1892	89.6
Islam	193	9.1
Others	27	1.3
Study level		
Undergraduate degree (currently being attended)	1510	71.5
Graduate degree (currently being attended)	602	28.5

SCD while diverging from it on the main source of information. Indeed, these authors reported that almost all students were aware of the existence of SCD, but the school was the main source of information at 84.6% [15]. However, despite this convergence, in DRC the involvement of educational institutions in raising awareness and education on SCD is still low and should be strengthened.

In 2010, WHO adopted and recommended a control strategy that included raising population awareness for SCD and strengthening primary prevention, believing that these measures could reduce the incidence of SCD and its related morbidity and mortality [2]. In the DRC, the implementation of these recommendations is still very little noticeable and our result reflects overall a still weak involvement of educational structures and health-care workers in raising awareness, information and education on SCD. The importance of education in the fight against this disease is highlighted in the study of Olatano et al. in Nigeria, who demonstrated that health education has considerably improved the knowledge of the population studied about SCD and their attitude towards it [13]. Although most of them have already heard of SCD, we have found insufficient knowledge about this disease since only 37.9% (95% CI: 35.9–40.0) said it is an inherited disease, 46.1% (95% CI: 44.0–48.2) said it is an acquired disease. In addition, 53.6% (95% CI: 51.5–55.7) said that the diagnosis of this disease is made by blood tests while 46.2% (95% CI: 44.1–48.3) talked about urine tests. Finally, the risk for children to develop SCD when both parents have SCD was ignored by 85.6%. This indicates that interventions to improve the knowledge of Kisangani University students regarding SCD are needed. Elsewhere, similar findings were reported in particular by the study of Alao et al. conducted among students in Nigeria in which it was observed that only 47% had a good knowledge of SCD [10] and that of Olubiyi et al which reported that only 34.4% of participants had a good understanding of the nature of the disease [14]. Owolabi et al. observed that the cause of SCD was known by only 38% of participants [12].

Most students, 79.6% (95% CI: 77.8–81.3) approved the need to screen for SCD before marriage, may be without understanding its importance since pre-marital screening was cited as a means of prevention by only 7.7% of students (95% CI: 6.6–8.9). This would then be in accordance with the Bazuaye et al. study in which 64% of students had either poor knowledge or were unaware of the importance of pre-marital screening of SCD [11]. Overall, the insufficient knowledge and/or misperception of SCD is reported in several studies conducted in SSA [4,7,10–12,15], the region with the highest prevalence in the world.

Table 2. Evaluation of the knowledge of 2112 participants on SCD.

Variable	Number (n = 2112)	% (95% CI)
Have you ever heard of SCD		
Yes	1963	92.9 (91.7–93.9)
No	149	7.1 (6.1–8.3)
If yes, Source of information (n = 1963)		
Health-care workers	461	23.5 (21.7–25.4)
Internet/media	256	13 (11.6–14.5)
Friends	473	24.1 (22.3–26.0)
Family	678	34.5 (32.5–36.6)
School	978	49.8 (47.7–51.9)
Cause of SCD		
Acquired	973	46.1 (44.0–48.2)
Hereditary	800	37.9 (35.9–40.0)
Don't know	339	16.1 (14.6–17.7)
How is SCD diagnosed?		
By blood tests	1132	53.6 (51.5–55.7)
By urinary tests	976	46.2 (44.1– 48.3)
Don't Know	4	0.2 (0.1–0.5)
What's risk for children to become sickle cell patient if both parents are sickle cell patients		
All the children	304	14.4 (13–16)
A quarter of the children	346	16.4 (14.9–18.0)
Half of the children	741	35.1 (33.1–3 7.2)
Don't know	721	34.1 (32.1–3 6.1)
Preventive measures of SCD		
Medical advices	1413	66.9 (64.9–68.9)
Pre-marital screening	163	7.7 (6.6–8.9)
Don't know	536	25.4 (23.6–27.3)

Note: CI, confidence interval.

Table 3. Evaluation of the attitude of 2112 participants on pre-marital screening of SCD.

Questions on attitude	Number (n = 2112)	% (95% CI)
Do you think it is necessary to do the pre-marital screening of SCD?		
Yes	1681	79.6 (77.8–81.3)
No	431	20.4 (18.7–22.2)
Can your partner's genotype influence the decision to marry him?		
Yes	1652	78.2 (76.4–79.9)
No	460	21.8 (20.1–23.6)
If your partner has SCD, are you going to marry him?		
Yes	379	18 (16.4–19.7)
No	1733	82 (80.3–83.6)
What should a couple do if they discover that their genotypes predispose him to give birth to a child with SCD?		
Separating	798	37.8 (35.8–39.9)
Continue with married life	281	13.3 (11.9–14.8)
Consult a doctor (genetic counseling)	1251	59.2 (57.1–61.3)
Don't know	200	9.5 (8.3–10.8)

Notes: CI, confidence interval; SCD, Sickle cell disease.

In the DRC, it is necessary that this disease be more popularized in the population and taught in both secondary and university schools as a cross-sectional course. This will improve the knowledge of students about the disease, and even their adherence to its pre-marital screening which is one of the pillars of its prevention. Preventive measures of this disease are very necessary in DRC where most of the advances in the management of SCD still not applicable.

The purchasing power and standard of living of students in the DRC is the same as that of the general population from which they come. As the DRC is ranked among the poorest countries in the world, access to information via the Internet, the audio-visual media and the written press remain limited for both students and the rest of the population. This could be one of the barriers to raising public awareness of SCD. Control strategies that take this setting into account are therefore necessary.

Study limitation

The main limitation of this study is the fact that it was conducted only at the University of Kisangani, which means that our findings may not be generalizable to the whole students of DRC. Despite this limitation, our study, first of its kind in the DRC to our knowledge, highlighted that the Kisangani University students' knowledge regarding SCD was poor and needs to be improved; education programs and motivational campaigns to be enhanced.

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Disclosure statement

No potential conflict of interest was reported by the author(s).

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