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Sickle Cell Trait in Kisangani: Prevalence and Opinion of Carriers towards the Choice of a Potential Carrier Spouse

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Abstract

Introduction: Sickle cell disease is one of the most common autosomal recessive inherited diseases. Its prevalence is increasing due to the perpetuity of carriers of the trait who are able to marry. Women aged 18 to 35 years constitute the most reproductive age group. This study was conducted with the aim of determining the prevalence of sickle cell trait among women aged 18 to 35 years and the attitude of women carriers towards the choice of a carrier spouse. **Materials and methods:** This was a cross-sectional descriptive study with analytical aims conducted from March to September 2024 in Kisangani. A total of 215 women aged 18 to 35 years presented for screening for sickle cell trait. This study described the following parameters: Sociodemographic data (age, level of education, socioeconomic level, marital status), obstetric and medical history (obstetric formula, sickle cell disease, high blood pressure, diabetes mellitus, asthma), knowledge of sickle cell disease (etiological classification, transmission, prevention, high-risk marriages, clinical manifestations, progression of the disease), attitude of the woman in relation to the choice of an AS spouse, as well as the reasons justifying each attitude. **Results:** The prevalence of sickle cell trait was 23.7% (51/215). A total of 64.3% of respondents had accepted the choice of spouse before confirmation of carrier status and 73.8% had refused after confirmation of carrier status. Choice was significantly related to age (p-value = 0.027), occupation (p-value = 0.015), parity (p-value = 0.039) and gesture (p-value = 0.034) before test. The ignorance of the

union at risk was associated with the risk (p = 0.005; OR: 9.10; CI 95%: 2.03 - 4.81) of accepting the choice of a spouse carrying the trait. **Conclusion:** The prevalence of sickle cell trait among women aged 18 to 35 years in Kisangani remains within the limits of that of the general population. The choice of a spouse carrying sickle cell trait is associated with the woman's age, her profession, parity, gestation and her knowledge about high-risk unions. Screening campaigns and health education sessions enable women carrying sickle cell trait to make a wise choice.

Keywords

Sickle Cell Trait, Prevalence, Attitude of Carriers, Choice of Spouse

1. Introduction

Sickle cell disease is one of the most common autosomal recessive inherited diseases. The genetic abnormality is due to the mutation on the beta chain of hemoglobin at the level of the seventh codon of beta-globin, by the substitution of glutamic acid by valine [1]. In sub-Saharan African countries where access to care and screening means are limited, the homozygous form constitutes a public health problem [2]. Nigeria and the Democratic Republic of Congo are the most affected countries, respectively second and third in the world after India [2] [3].

Few sickle cell patients reach reproductive age, and sickle cell disease is often associated with fertility disorders in both men and women. In men, it is associated with puberty disorders, spermatogenesis disorders, and erectile dysfunction. In women, apart from puberty disorders and menstrual disorders, sickle cell disease is associated with a decrease in ovarian reserve, causing subfertility [4]. Pregnancy in sickle cell patients is often complicated by abortions and premature birth, low birth weight, and hypertensive disorders [5].

In view of the short life expectancy of sickle cell patients and the fertility disorders caused by sickle cell disease, this disease should normally disappear over time or become rare in the population [6]. But on the contrary, the prevalence of sickle cell disease is only increasing over time [7]. This increase of prevalence could be due to the perpetuity of sickle cell trait carriers, capable of marriage and procreation. Over time, trait carriers (AS) have been considered as patients with few symptoms and the notion of genetic transmission of the disease has always been well known to the African population [8], what makes marriage stigmatizing between two carriers with sickle cell trait.

Women aged 18 to 35 years are the most reproductive age group, they are exposed to less risk related to motherhood [9] [10]. An action carried out within this age group of women, in relation to the choice of spouse considering the hemoglobin status, would be crucial in preventing the birth of children with sickle cell disease. To achieve this, it is important to determine beforehand the attitude of these women towards the choice of a spouse carrying the trait.

Most African countries remain attached to traditional practices, including the Democratic Republic of Congo, marriage is the fulfillment of a dream for most women, because a married woman is an accomplished woman. For African society, the purpose of marriage is to have children, the latter are a source of pride, happiness and condition the stability of a marriage [11] [12]. This societal pressure sometimes forces women to marry without prior, whatever the risk. But it also forces women to fulfill their duty of motherhood, because infertility in Africa is considered as a sacrilege, and it is the woman who is held primarily responsible [13]. In a context of countries with limited resources and societal pressure linked to motherhood, many unions are founded without carrying out premarital examinations, including screening for sickle cell trait [14]. Some studies conducted in Kinshasa in the Democratic Republic of Congo have estimated the prevalence of sickle cell trait at between 20% and 40% [15] [16]. This prevalence could thus determine an increased risk of marriages between carriers of sickle cell trait, thus justifying a high prevalence of sickle cell patients.

This study was conducted with the aim of determining the prevalence of sickle cell trait among women aged 18 to 35 years and the attitude of women carriers of sickle cell trait towards the choice of a carrier spouse after having learned of their carrier status of the trait and to determine the factors associated with their choices before and after the test.

2. Material and Method

2.1. Type and Environment of Study

This was a cross-sectional descriptive study with analytical aims conducted from March to September 2024 at the University Clinics of Kisangani (Tshopo Province, North-East of the RDC). The University Clinics of Kisangani served as the research site. This establishment is the only one to organize sickle cell disease screening campaigns over the last decade in the city of Kisangani, the last of which took place between March and October 2024.

2.2. Study Population

The present study involved 215 women aged 18 to 35 years who presented after awareness-raising for sickle cell trait screening and who consented to participate in the study. Excluded from this study were all women who recognized themselves as carriers of the sickle cell trait or who had a homozygous sickle cell family member, married women.

2.3. Sampling and Sample Size

This was a temporary and voluntary sampling that registered women who consented to participate in the study.

2.4. Procedure

The women were received by an investigator, a consent form written in French

and local languages (Swahili and Lingala) was given to them, so that the respondent could become aware of the study before giving her approval. Once consent was obtained, a pre-established questionnaire was given to the respondent and the following information was sought: Sociodemographic data (age, level of education, socioeconomic level, marital status), obstetric and medical history (obstetric formula, sickle cell disease, high blood pressure, diabetes mellitus, asthma), knowledge of sickle cell disease (etiological classification, transmission, prevention, high-risk marriages, clinical manifestations, progression of the disease), attitude of the woman in relation to the choice of an AS spouse, as well as the reasons justifying each attitude.

After completing the form, the respondent was referred to the research laboratory of the University Clinics of Kisangani for screening sickle cell trait and the result was immediately returned to the respondent after the test. For the AS respondents who were registered in this study, an appointment was made for a health education session on sickle cell disease. After the session, we asked again the question on the attitude in relation to the choice of an AS spouse as well as the reasons justifying each attitude and the answers were reported on the same collection form. For the AS respondents who were not included in this study, the same health education session was organized for them on the same day of screening.

2.5. Hemoglobin Screening

After disinfection of the elbow crease, 1 mL of venous blood was collected by venipuncture and the sample was placed in a procoagulant tube (dry tube or immunized tube). A quantity of 1.5 µL blood was immediately withdrawn for hemoglobin S screening. Screening was done using the HemoTypeSC manufactured by Silver Lake Research Corporation, 1300 West Optical Drive Azusa, THAT 91702, USA Hemotype.com/ISO 134845. It is a rapid competitive lateral flow test incorporating monoclonal antibodies for the detection of hemoglobin A, S and C. The test followed the procedure determined by the supplier [17].

L'interpretation of the hemoglobin type test results will be made by comparison as shown in **Figure 1**.

2.6. Data Analysis

The collected data were entered and encoded using the Excel spreadsheet (Microsoft Excel, CDC, 2010) and then imported for analysis using R software version 4.4.1 (2024-06-14 ucrt). The results were presented as percentages with their 95% confidence intervals. To search for the determinants of the choice of spouse, we carried out simple logistic regression. The significance threshold was set at $P < 0.05$.

2.7. Ethical Considerations

Participation in the study was voluntary, written consent was obtained from the participants. The data were used only by the people involved in the study.

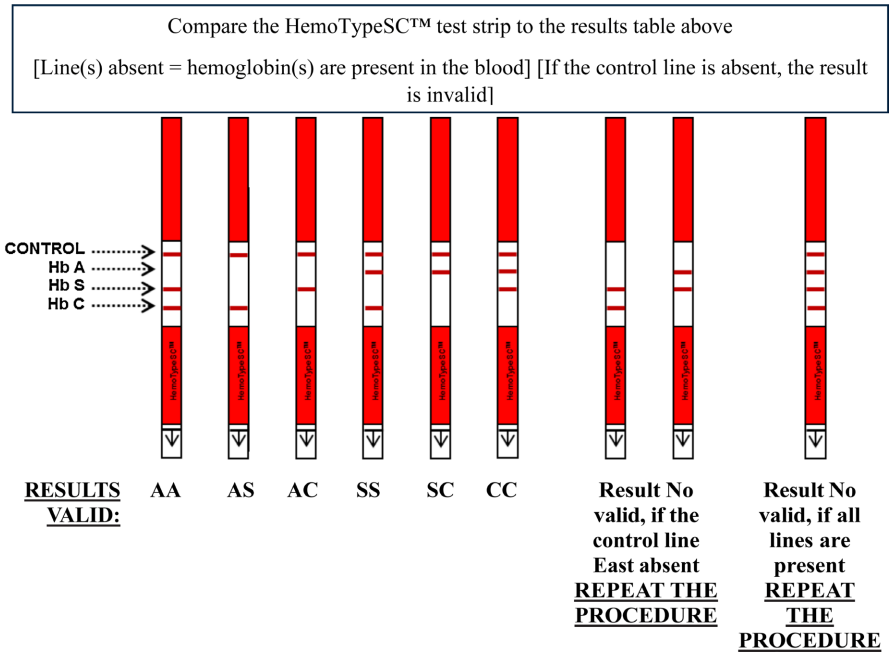

Figure 1. Interpretation of the HemoTypeSC test (Image taken from https://www.vortexmeds.com/hemotypesc.php).

A number was assigned to each participant to ensure anonymity during and after the study. This study received approval from the ethics committee of the University of Kisangani: UNIKIS/CER/022/2024.

3. Results

3.1. Prevalence of Sickle Cell Trait

Of 215 women aged 18 to 35 years registered during our study, 51 women were screened as carriers of the sickle cell trait, representing a prevalence of 23.7%. Among them, 9 were excluded. We finally retained a sample of 42 respondents.

3.2. Socio-Demographic Data

In total, 64.3% of respondents were under 25 years old, 78.6% had a higher level of education, 78.6% were not employed and 78.6% had no family history of sickle cell disease (Table 1).

Table 1. Distribution of respondents according to sociodemographic data and family history of sickle cell disease.

Features	n = 42	Percentage
Age groups (years)		
18 - 25	27	64.3
26 - 30	9	21.4
31 - 35	6	14.3

Continued

Level of education		
Superior	33	78.6
Secondary	9	21.4
Job		
Unemployed	32	76.2
With employment	10	23.8
Family history of sickle cell disease		
No	33	78.6
Yes	9	21.4

Among the respondents, 78.6% were nulliparous and 61.9% were nulligest and 80.9% had no antecedent of abortion (Table 2).

3.3. Gyneco-Obstetric Antecedents

Table 2. Distribution of respondents according to gyneco-obstetric history.

Variables	n = 42	Percentage
Parity		
Nulliparous	33	78.6
At least one birth	9	21.4
Gesture		
Nulligest	26	61.9
At least one pregnancy	16	38.1
Abortion		
0	34	80.9
1 - 2	6	14.3
≥3	2	4.8

3.4. Knowledge about Sickle Cell Disease

Most respondents knew that sickle cell disease is a hereditary disease (42.9%), incurable (59.5%), the type of union at risk (76.19%), but were unaware of the means of prevention (40.5%). This was represented in Table 3.

3.5. Choice of Spouse Carrying Hemoglobin AS

3.5.1. Reasons for Choice

Table 4 shows that 64.3% of respondents accepted the choice of a spouse carrying hemoglobin AS. before confirmation of sickle cell trait carrier status, giving as a reason in 33.3% that not all children will be SS and that marriage was a gift from God in 29.6%.

Table 3. Distribution of respondents according to knowledge of sickle cell disease.

Variables	n = 42	Percentage
Origin of the disease		
Hereditary	18	42.9
Mystical-religious	10	23.8
Contagious	3	7.1
Ignored	11	26.2
Evolution of the disease		
Incurable	25	59.5%
Curable	10	23.8%
Ignored	7	16.7%
Knowledge of the risk union		
Yes	32	76.19
No	10	23.81
Prevention		
Premarital examinations	15	35.7
Newborn screening	10	23.8
Ignored	17	40.5

Table 4. Distribution of respondents according to choice of carrier spouse and reasons for choice before confirmation of sickle cell trait carrier status.

Variables	Staff	Percentage
Agreement for choice of AS spouse	**n = 42**	
YES	27	64.3
NO	15	35.7
Reasons for YES	**n = 27**	
Not all children will be SS	9	33.3
Marriage is a gift from God	8	29.6
Capable of PEC	3	11.1
Child SS can be useful	4	14.8
Curable disease	1	3.7
I won't have SS	2	7.4
Reasons for NO	**n = 15**	
Family instability	5	33.3
Source of Divorce	3	20.0
Source of Poverty	5	33.3
Guilt	2	13.3

The results below show that 73.8% of respondents had refused the choice of the spouse carrying AS hemoglobin after confirmation of the status of carrier of sickle cell trait after screening for sickle cell trait, with poverty as the reason in 38.7% (Table 5).

Table 5. Distribution of respondents according to choice of carrier spouse and reasons for choice after confirmation of sickle cell trait carrier status.

Variables	Staff	Percentage
Agreement for choice of AS spouse	**n = 42**	
YES	11	26.2
NO	31	73.8
Reasons for YES	**n = 11**	
Curable disease	1	9.1
Capable of PEC	2	18.2
Not all children will be SS	6	54.5
Child SS can be useful	2	18.2
Reasons for NO	**n = 31**	
Family instability	6	19.4
Making an innocent suffer	5	16.1
Marriage Gift of God	4	12.9
Source of Divorce	4	12.9
Source of Poverty	12	38.7

3.5.2. Sociodemographic Characteristics and Knowledge of Sickle Cell Disease

The table below shows that the choice over a carrier spouse was significantly linked to age and profession before the test, with p-values of 0.027 and 0.015 respectively (Table 6).

Table 6. Distribution of the choice of respondents before the test in relation to sociodemographic characteristics and knowledge of sickle cell disease

Variables	YES n = 27	NO n = 15	p-value
Age group (years)			**0.027**
18 - 25	12 (44.4%)	13 (86.7%)	
26 - 30	9 (33.3%)	1 (6.7%)	
31 - 35	6 (22.2%)	1 (6.7%)	
Level of study			0.5
Secondary	7 (25.9%)	2 (13.3%)	
Superior	20 (74.1%)	13 (86.7%)	

Continued

Occupation			**0.015**
With profession	12 (44.4%)	1 (6.7%)	
Without profession	15 (55.6%)	14 (93.3%)	
Etiological classification			0.7
Contagious	2 (7.4%)	1 (6.7%)	
Hereditary	13 (48.1%)	5 (33.3%)	
Mystical-religious	5 (18.5%)	5 (33.3%)	
I don't know	7 (25.9%)	4 (26.7%)	
Evolution of the disease			0.13
Curable	10 (37.0%)	1 (6.7%)	
Incurable	13 (48.1%)	11 (73.3%)	
I don't know	4 (14.8%)	3 (20.0%)	
Prevention			0.13
Newborn screening	4 (14.8%)	6 (40.0%)	
Premarital examination	12 (44.4%)	3 (20.0%)	
I don't know	11 (40.7%)	6 (40.0%)	
Knowledge of the risky union			>0.9
No	8 (29.6%)	4 (26.7%)	
Yes	19 (70.4%)	11 (73.3%)	

The table below shows that the choice of the respondents regarding a carrier spouse was significantly linked to knowledge of the union at risk after the test, with a p-value of 0.006 (Table 7).

Table 7. Distribution of the choice of respondents after testing in relation to sociodemographic characteristics and knowledge of sickle cell disease.

Variables	YES n = 11	NO n = 31	p-value
Age groups (years)			0.5
18 - 25	5 (45.5%)	20 (64.5%)	
26 - 30	2 (18.2%)	5 (16.1%)	
31 - 35	4 (36.4%)	6 (19.4%)	
Level of study			0.7
Secondary	3 (27.3%)	6 (19.4%)	
Superior	8 (72.7%)	25 (80.6%)	
Occupation			0.3
With profession	5 (45.5%)	8 (25.8%)	

Continued

Without profession	6 (54.5%)	23 (74.2%)	
Etiological			0.4
Contagious	1 (9.1%)	2 (6.5%)	
Hereditary	7 (63.6%)	11 (35.5%)	
Mystical-religious	1 (9.1%)	9 (29.0%)	
I don't know	2 (18.2%)	9 (29.0%)	
Evolution of the disease			0.2
Curable	5 (45.5%)	6 (19.4%)	
Incurable	4 (36.4%)	20 (64.5%)	
I don't know	2 (18.2%)	5 (16.1%)	
Prevention			0.3
Newborn screening	1 (9.1%)	9 (29.0%)	
Premarital examination	6 (54.5%)	9 (29.0%)	
I don't know	4 (36.4%)	13 (41.9%)	
Knowledge of the risky union			**0.006**
No	7 (63.6%)	5 (16.1%)	
Yes	4 (36.4%)	26 (83.9%)	

In logistic regression, women who did not know about risky marriage were 9.10 times more likely to accept the choice of a carrier spouse (P-value = 0.005) (Table 8).

Table 8. Logistic regression analysis between the choice of carrier spouse and knowledge of risky marriage after testing.

Variables	Staff[1]	Raw gold			OR corrected		
		OR[2]	95% CI[2]	p	OR[2]	95% CI[2]	p-value
Knowledge of risky marriage							
Yes	13.3% (4/30)	—	—		—	—	
No	58.3% (7/12)	9.10	2.03 - 4.81	0.005	9.10	2.03 - 48.1	0.005

3.5.3. Gyneco-Obstetric History

The results showed that before the test, the choice of a joint carrier was significantly linked to parity and gestation with a p value of 0.039 and 0.034 respectively (Table 9).

The results showed that after testing, the choice of the carrier spouse was not statistically linked to any gyneco-obstetric history (Table 10).

4. Discussion

4.1. Prevalence Of Sickle Cell Trait

In our study, we found a prevalence of 23.7% of sickle cell trait among women

Table 9. Distribution of the choice of respondents before the test in relation to gyneco-obstetric history.

Variables	YES N = 27	NO N = 15	p-value
Parity			**0.039**
Nulliparous	18 (66.7%)	15 (100.0%)	
Pauciparous	5 (18.5%)	0 (0.0%)	
Multiparous	4 (14.8%)	0 (0.0%)	
Gesture			**0.034**
Nulligestes	13 (48.1%)	13 (86.7%)	
Paucigestes	8 (29.6%)	2 (13.3%)	
Multigestures	6 (22.2%)	0 (0.0%)	
Abortion			0.8
0	21 (77.8%)	13 (86.7%)	
1 - 2	4 (14.8%)	2 (13.3%)	
≥3	2 (7.4%)	0 (0.0%)	
Deceased child			0.5
None	25 (92.6%)	15 (100.0%)	
A	2 (7.4%)	0 (0.0%)	

Table 10. Distribution of the choice of respondents after the test in relation to gyneco-obstetric history.

Variables	YES N = 11	NO N = 31	p-value
Parity			0.3
Multiparous	2 (18.2%)	2 (6.5%)	
Nulliparous	7 (63.6%)	26 (83.9%)	
Pauciparous	2 (18.2%)	3 (9.7%)	
Gesture			0.2
Multigestures	3 (27.3%)	3 (9.7%)	
Nulligestes	7 (63.6%)	19 (61.3%)	
Paucigestes	1 (9.1%)	9 (29.0%)	
Abortion			0.2
1 to 2	0 (0.0%)	6 (19.4%)	
None	10 (90.9%)	24 (77.4%)	
Three	1 (9.1%)	1 (3.2%)	
Deceased child			0.5 [2]
None	10 (90.9%)	30 (96.8%)	
A	1 (9.1%)	1 (3.2%)	

aged 18 to 35 years in Kisangani. This value is higher than those of Guilherme *et al.* [18], Fenomanana *et al.* [19] and Teguete *et al.* [20] with the values of 13.45%, 1.17% and 18.7% respectively. We think that the prevalence in our study could be justified by the endemic nature of sickle cell disease in the Democratic Republic of Congo, the second most affected in Africa [21]. In contrast, value obtained in this study is lower than those found by Baffour *et al.* [22] with the prevalence of 41.7%; this could be justified by a small sample size of 12 donors in Samuel Antwi-Baffour's study.

We found a prevalence of sickle cell trait close to that found in the general Congolese and Nigerian population [23]-[26], justified by the endemic nature and autosomal recessive transmission of the disease.

4.2. Choice of Spouse Carrying Hemoglobin AS

During our study, before confirmation of hemoglobin status and health education, 64.3% of respondents had accepted the union with a partner carrying the sickle cell trait. But after testing confirming the sickle cell trait carrier status and health education, the proportion of respondents who had accepted the union with a partner carrying the sickle cell trait had significantly decreased. This attests to the impact of screening associated with health education on the control of health phenomena [16] [27].

Before screening and health education, the choice of a spouse carrying the sickle cell trait was associated with age and profession. Indeed, the older the woman was, the more she tended to agree to marry a carrier of the sickle cell trait. This could be justified by the fact that it is known that female fertility decreases with age [28], this could impact the chances of getting married, especially in the context of Black Africa where motherhood is the expression of a successful marriage and where the woman is held responsible for the couple's infertility [11] [12]. Women seeing their chances of getting married decrease with age, are sometimes ready to marry without objectivity as soon as an opportunity arises.

In our study, before testing, women who had a profession tended to accept the choice of a sickle cell trait carrier, while those who did not have a profession tended to refuse. This could be justified by the fact that the majority of the population knows that the survival of sickle cell children requires a financial cost that is almost beyond the reach of the majority of the population [29], justified by the eighth position among the poorest countries in the world occupied by the Democratic Republic of Congo, with an unemployment rate estimated at more than 80% of the general population [30].

After testing and health education, the choice was associated with knowledge of the risky union. In bivariate analysis, most women who knew the union that exposed them to the risk of having children with sickle cell disease refused the choice of a spouse carrying the sickle cell trait. However, those who were unaware tended to accept the choice of a spouse carrying the trait. After logistic regression, the same trend was observed. We believe that these objective trends in the choice

of spouse could be due to health education sessions that we had provided, but also to the various awareness campaigns for different studies conducted on sickle cell disease in Kisangani over the last decade [2] [23] [31] [32].

It was observed that in our series, the choice of a carrier spouse before screening and health education was significantly related to parity and gestation. Women who had already given birth were more likely to accept the choice of a carrier spouse. We believe that this trend could be due to the different considerations of society towards single mothers. Indeed, in some African societies, it is not admissible to be a mother without having a husband, which means that single mothers and women see their chances of having a husband reduced, which exposes them to confiding in the first spouse who comes along [33]-[35].

Limit of the study

The limitation of this study is that it was on a single site, with a small sample, hence the results of this study cannot be generalized. Nevertheless, this is a first study of its kind in the Democratic Republic of Congo and one of the rare in the literature.

5. Conclusions

The prevalence of sickle cell trait among women of childbearing age (18 to 35 years) in our series was 23.7% and remains within the limits of those of the general population. Most respondents were aged 18 to 25 years (64.3%), had a higher level of education (78.6%), unemployed (76.2%) and without a family history of sickle cell disease (78.6%). The majority knew the hereditary origin and the incurable course of the disease but were unaware of the means of prevention.

Before the test and health education, 64.3% of respondents had agreed to marry a potential spouse with sickle cell trait, compared to 35.7% who had refused. After the test and health education, 26.2% accepted against 73.8%. Before the test, this choice was significantly associated with age, profession, parity and gestation. But after the test and health education, the choice was not associated with knowledge of risky marriage.

This study showed that screening campaigns and health education sessions allow women with sickle cell trait to make a wise choice that can contribute to reducing the frequency of sickle cell disease in the Democratic Republic of Congo. The Congolese government should set up centers to raise awareness against sickle cell disease outside of mass screening periods.

Conflicts of Interest

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

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