KNOWLEDGE, ATTITUDES, AND PRACTICES OF THE ADULT POPULATION REGARDING SICKLE CELL DISEASE IN LUBUMBASHI (D.R. CONGO)

Tshibumbu Kabeya Edouard[1], Kasamba Ilunga Eric[1], Balaka Ekwalanga Michel[1], Shongo Ya Pongombo Mick[2], Kazadi Lubobo Claude[1], Ndibualonji Badibanga Victor.[3]

[1]Department of Biomedical Sciences, Faculty of Medicine, University of Lubumbashi, D.R. Congo.
[2]Department of Pediatrics, Faculty of Medicine, University of Lubumbashi, D.R. Congo.
[3]Biochemistry Unit, Faculty of Veterinary Medicine, University of Lubumbashi, D.R. Congo.
Correspondence: **Tshibumbu Kabeya Edouard**
Department of Biomedical Sciences, Faculty of Medicine, University of Lubumbashi.
Tel.: +243 810 567 793 / +243 995 361 550
E-mail: edouardkabey@gmail.com

Abstract

Background: Sickle cell disease is a hereditary disorder widespread throughout the world. In the D.R. Congo, approximately 40,000 children with sickle cell disease are born each year. However, this disease remains poorly known among the population, contributing to high mortality rates.

Objective: To assess the knowledge, attitudes, and practices of adults regarding sickle cell disease in Lubumbashi to improve prevention and management strategies.

Methods: A descriptive cross-sectional study was conducted over a three-month period (July 1 to September 30, 2022), including a sample of 449 adults. Data collection was performed using a structured questionnaire. All data were entered and analyzed using Epi Info software, version 3.5.4.

Results: Among the 449 respondents, 409 (91.09%) had already heard of sickle cell disease. The main sources of information cited were health workers (36.67%), followed by family members and the media. However, more than half of the respondents (54.77%) were unaware of the disease's cause.

Conclusion: The majority of respondents were aware of the existence of sickle cell disease, but detailed knowledge about its cause, manifestations, and prevention remains limited. Therefore, a structured communication, education, and information program for the Congolese population is necessary.

Keywords: Sickle Cell Disease, Knowledge Attitudes Practices, Adults, Lubumbashi, Democratic Republic Of Congo.

1. INTRODUCTION

Sickle cell disease is a hereditary red blood cell disorder widespread globally, characterized by the production of pathological hemoglobin S (HbS) (1), responsible for vaso-occlusive crises (2). This pathology affects approximately 30 million individuals worldwide and represents a major public health problem associated with significant morbidity and mortality(3). It is particularly prevalent among sub-Saharan African populations, as

well as those from the Americas, Caribbean, India, Middle East, and Mediterranean basin(4,5), primarily affecting low-income country populations (6).

The Democratic Republic of Congo (DRC) has the second highest sickle cell disease incidence rate in Africa after Nigeria. The disease prevalence in this Central African country is estimated at 0.97% to 1.4% among newborns, with an incidence of 30,000 to 40,000 sickle cell births annually (7). Approximately 2% of these births involve homozygous children. This disease remains poorly known among the population, explaining the high mortality in this resource-limited context (8,9).

In this context, it is appropriate to assess the knowledge, attitudes, and practices (KAP) of adults regarding sickle cell disease in Lubumbashi to strengthen prevention strategies and improve disease management.

2. MATERIALS AND METHODS

The study was conducted in Lubumbashi, the second most populous city in the Democratic Republic of Congo, comprising seven communes: Annexe, Lubumbashi, Kampemba, Ruashi, Kenya, Katuba, and Kamalondo (10).

This was a single-pass cross-sectional study conducted at the household level from July 1 to September 30, 2022. The sample included 449 adults selected through two-stage simple random sampling:

1. Random selection of health areas proportional to their population.
2. Systematic random selection of households in each area, with the first household determined by a random number generated in Excel.

Inclusion criteria were: age ≥18 years, permanent residence in Lubumbashi for at least six months, and informed consent. Exclusion criteria included cognitive impairment or refusal to participate.

Nineteen students from the School of Public Health at the University of Lubumbashi, specifically trained for the survey, conducted the interviews. Sample size (n = 449) was calculated to estimate a sickle cell disease awareness prevalence of approximately 50% with ±5% absolute precision and 95% confidence level. The calculation accounted for Lubumbashi's finite adult population and an anticipated 10% refusal rate. The final number of participants exceeded the minimum required (n = 384), ensuring adequate statistical power.

The study received approval from the University of Lubumbashi Medical Ethics Committee (UNILU/CEM/100/2022, June 3, 2022). All data were processed anonymously.

A standardized, pre-tested questionnaire was administered through direct face-to-face interviews. The pretest involved 30 adults (not included in the main study) and assessed clarity (comprehension rate >90%), internal consistency (Cronbach's $\alpha = 0.78$ for knowledge items), and inter-observer reproducibility ($\kappa = 0.82$). Minor adjustments were made post-pilot phase.

The questionnaire comprised three main sections:

1) Sociodemographic data (7 items): commune, sex, age, marital status, number of children aged 0-5 years, education level, occupation.

2) Initial screening question: "Have you ever heard of sickle cell disease?"

- Participants answering "Yes" (n = 409; 91.09%): continued with subsequent sections.
- Participants answering "No" (n = 40; 8.91%): ended the interview.

3) General knowledge (9 items), attitudes and practices (6 items): administered only to the 409 informed participants.

Data were analyzed using Epi Info software. Associations between categorical variables were tested using the chi-square (χ^2) test with a 5% significance threshold ($\alpha = 0.05$).

3. RESULTS

3.1. Sociodemographic characteristics of participants

The study included 238 women (53.0%) and 211 men (47.0%), yielding a sex ratio of 0.89. Age distribution was: 30.5% (18-29 years), 42.3% (30-39 years), 17.2% (40-49 years), and 10.0% (≥50 years).

Regarding residence, 21.2% lived in Lubumbashi commune and 19.6% in Annexe commune. Marital status comprised: 298 married (66.4%), 126 single (28.1%), 16 divorced/separated (3.6%), and 9 widowed (2.0%).

Education levels were: 223 secondary (49.7%), 176 higher (39.2%), 27 primary (6.0%), and 23 unschooled (5.1%). Occupational distribution included: 121 unemployed (26.9%), 90 housewives (20.0%), 83 private sector employees (18.5%), 69 civil servants (15.0%), 64 artisans (14.3%), and 22 merchants (4.9%).

Regarding children under 5 years: 202 (45.0%) had none, 109 (24.3%) had two, 93 (20.7%) had one, 40 (8.9%) had three, 3 (0.7%) had four, and 2 (0.5%) had five.

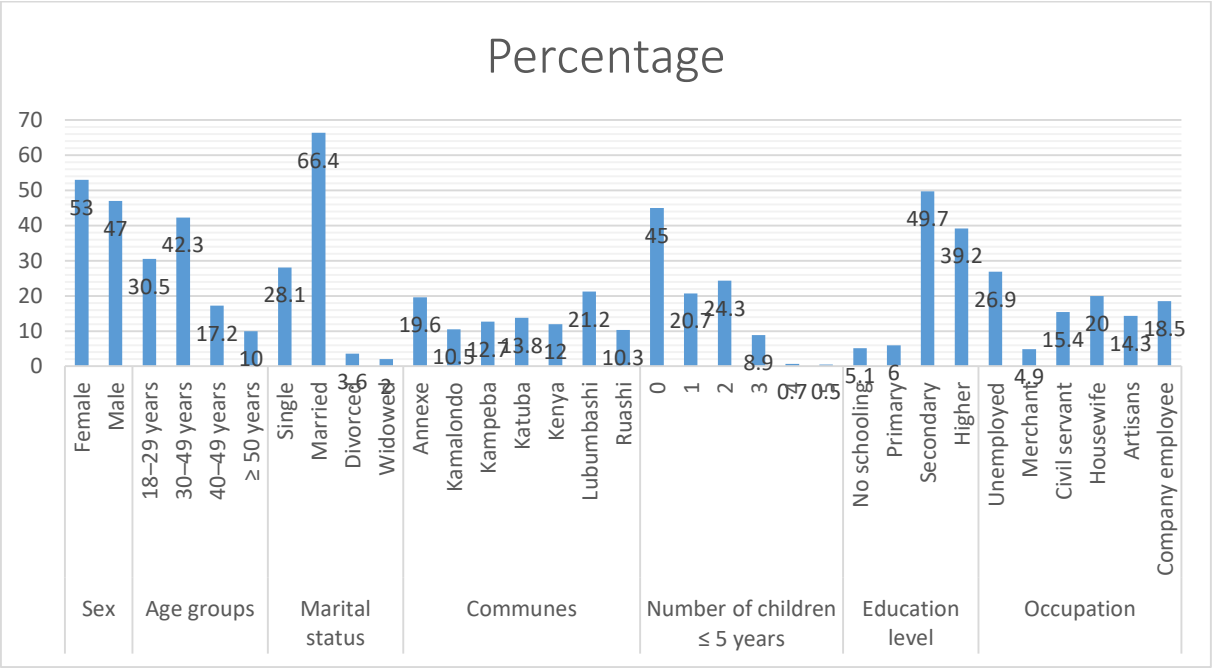

Figure 1. Sociodemographic characteristics of the respondents

3.2. Knowledge of respondents on sickle cell disease

Table I. Distribution of respondents according to their knowledge of sickle cell disease (n = 449)

Assessed domain	Modality	n (%)	95% CI
Having heard about sickle cell disease	Yes	409 (91.09 %)	88.47 – 93.71
	No	40 (8.91 %)	6.29 – 11.53
Cause of sickle cell disease	Abnormal Hb	185 (45.23 %)	40.41 – 50.06
	Do not know	224 (54.77 %)	49.94 – 59.59

Clinical signs of sickle cell disease	Good	216 (52.81 %)	47.97 – 57.65
	Poor	193 (47.19 %)	42.35 – 52.03
Triggering factors of crises	Good	106 (25.92 %)	21.67 – 30.16
	Poor	303 (74.08 %)	69.84 – 78.33
Possible complications	Good	90 (22.00 %)	17.99 – 26.02
	Poor	319 (78.00 %)	73.98 – 82.01
Other names for sickle cell disease	Anaemia	74 (18.09)	14.4 – 21.8
	SS	242 (59.17)	54.4 – 63.9
	Do not know	93 (22.74)	18.7 – 26.8
Age at onset of the disease	0–1 year	214 (52.32)	47.5 – 57.2
	1–5 years	110 (26.89)	22.6 – 31.2
	> 5 years	85 (20.78)	16.8 – 24.7
Forms of sickle cell disease	Mild	168 (41.08)	36,3 – 45,9
	Severe	203 (49.63)	44.8 – 54.5
	Others	38 (9.29)	6.5 – 12.1
Knowledge of prevention	Yes	298 (72.86)	68.55 – 77.17
	No	111 (27.14)	22.83 – 31.45
Can the disease be cured?	Yes	124 (30.32)	25.86 – 34.77
	No	285 (69.68)	65.23 – 74.14
Reasons for non-cure	Hereditary	105 (25.66)	21.4 – 29.9
	Incurable	217 (53.05)	48.2 – 57.9
	Blood disease	35 (8.60)	5.9 – 11.3
	Bad origin	6 (1.43)	0.3 – 2.6
	No treatment	54 (13.26)	10.0 – 16.5

"Knowledge was rated as good if ≥60% correct responses per domain (signs, crises, complications), poor if <60%. Threshold validated by KAP literature and local expertise."

Table I shows that among the 449 participants, 409 (91.09%) reported having heard of sickle cell disease. Among these, less than half (185, or 45.23%) knew the cause of the disease as hemoglobin abnormality.

Knowledge of clinical signs was rated good in 216 participants (52.81%) and poor in 193 (47.19%). In contrast, the majority had poor knowledge of crisis triggers (106 good [25.92%] vs 303 poor [74.08%]) and disease complications (90 good [22.00%] vs 319 poor [78.00%]).

Regarding other names for sickle cell disease, 242 participants (59.17%) mentioned "SS", 74 (18.09%) "anemia", and 93 (22.74%) knew no other name. The age of disease onset was estimated by 214 (52.32%) participants as 0-1 year, 110 (26.89%) as 1-5 years, and 85 (20.78%) as >5 years.

For clinical forms, nearly half mentioned a severe form (49.63%), 41.08% (168) the minor form, and 38 (9.29%) knew no forms. Regarding prevention, 298 participants (72.86%) reported knowing preventive measures. Concerning curability, 124 (30.32%) believed sickle cell disease could be cured, while 285 (69.68%) thought it incurable, mainly citing incurability (53.05%), hereditary nature (23.66%), blood disease (8.60%), or poor origin (1.43%).

These results indicate that although most participants had heard of sickle cell disease, detailed knowledge of its causes, signs, complications, and management possibilities remains limited, highlighting the need for enhanced health education and awareness.

3.3. Attitudes and practices of participants regarding sickle cell disease cases

Figure 2 presents the various sources of information about sickle cell disease and the attitudes displayed by participants toward this pathology. Data show that the main source of information for 150 participants (36.7%) was health workers, followed by family (82 [20.1%]) and neighborhood (80 [19.6%]).

Additionally, 343 (83.9%) had encountered a sickle cell disease case, either within family or elsewhere. Among them, 20 (5.8%) reported it was their own child. Regarding disease recognition, 201 participants (58.6%) identified it through clinical signs, while 142 (41.4%) learned through laboratory tests.

The majority (325 [94.8%]) reported seeking modern medicine during sickle cell crises. Other options included church (10 [2.9%]) and traditional medicine (8 [2.3%]).

Reasons for seeking care varied: correct management was the main reason for 265 (77.26%). Others cited health facility proximity (28 [8.2%]), spiritual reasons (22 [6.4%]), lack of financial means (20 [5.8%]), or health insurance subscription (8 [2.3%]).

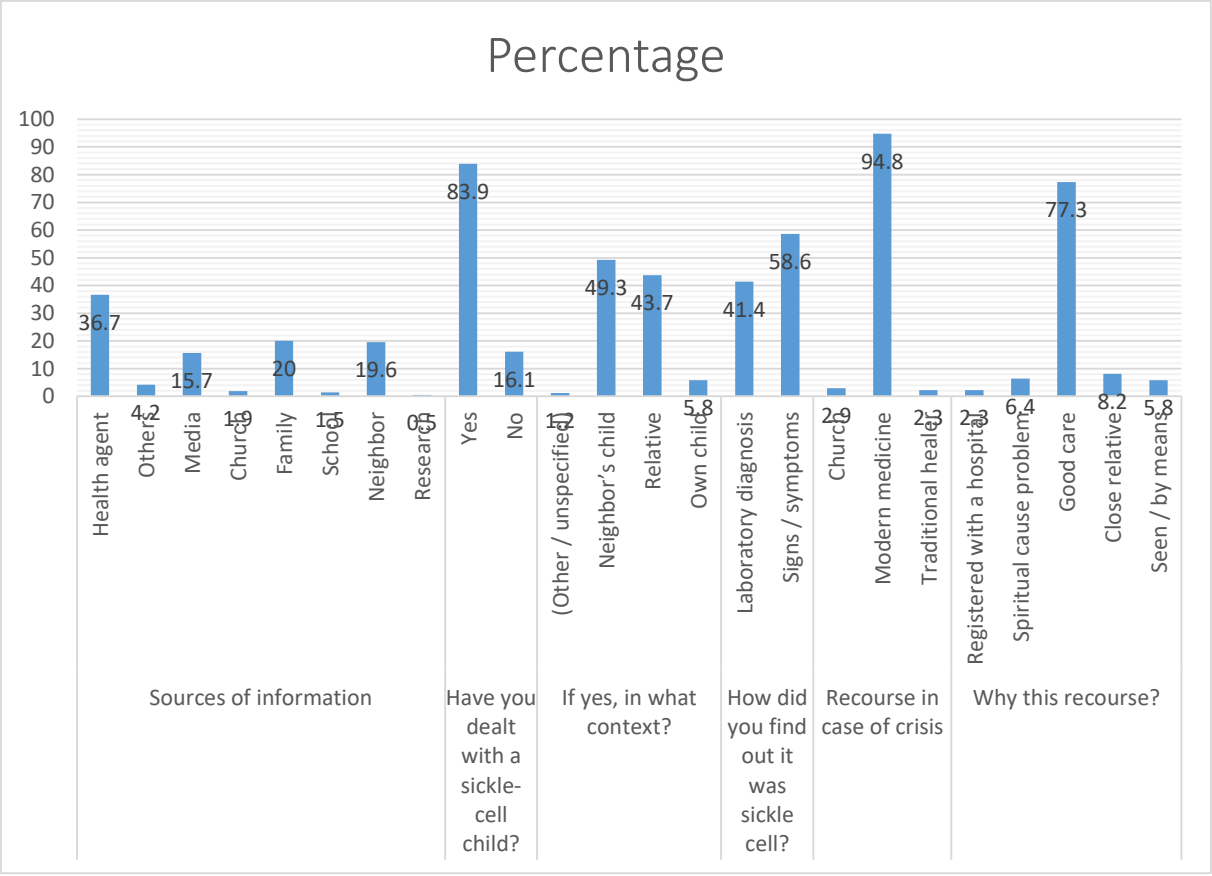

Figure 2. Distribution of respondents according to their attitudes and practices when faced with a case of sickle cell disease

3.4. Factors associated with knowledge and preventive practices regarding sickle cell disease

Table II. Sociodemographic factors significantly associated with knowledge and preventive practices regarding sickle cell disease (n = 409)

Factor (comparison category)	Associated variable	χ^2	p	RR (95% CI)
Marital status (Married vs others)	Knowledge of causes	5.74	0.017	1.28 (1.08–1.52)
Marital status (Married vs others)	Preventive practice	4.64	0.031	1.22 (1.02–1.46)

Age (≥30 years vs <30 years)	Preventive practice	4.18	0.041	1.25 (1.01–1.55)
Education level (Unschooled vs Educated)	Having heard of it	11.35	<0.001	0.72 (0.58–0.89)
Education level (Unschooled vs Educated)	Knowledge of causes	8.29	0.004	0.81 (0.65–1.01)
Education level (Unschooled vs Educated)	Preventive practice	9.67	0.002	0.75 (0.61–0.91)

Chi-square (χ^2) test applied; significance threshold $p < 0.05$.

Table II shows the following:

- Married participants had better knowledge of causes ($\chi^2 = 5.74$; $p = 0.017$) and more frequently adopted adequate preventive practices ($\chi^2 = 4.64$; $p = 0.031$) than other categories. Similarly, individuals aged 30 years and older showed more appropriate practices than younger participants ($\chi^2 = 4.18$; $p = 0.041$).
- Education level emerged as the main determinant: unschooled participants had a significantly lower probability of having heard of sickle cell disease ($\chi^2 = 11.35$; $p < 0.001$), knowing its causes ($\chi^2 = 8.29$; $p = 0.004$), and applying adequate preventive practices ($\chi^2 = 9.67$; $p = 0.002$).
- Non-significant variables (sex and occupation) were not included to simplify presentation.

These results reveal the influence of key sociodemographic variables on knowledge and preventive practices, which are explored in the discussion.

4. DISCUSSION

In this survey, the proportion of women (53.0%) was slightly higher than that of men (47.0%). This difference could be explained by the greater availability of women, who are often less involved in professional activities outside the home in this context. It might also reflect lower participation among men, possibly due to a less favorable attitude toward health surveys, as suggested by Tusuubira et al. (11).

The most represented age group was 30–39 years (42.3%), followed by 18–29 years (30.5%). These predominant groups correspond to periods of high reproductive and family activity, suggesting that young and middle-aged adults are generally more available and more concerned with family-related health issues in community surveys (12).

Most respondents resided in Lubumbashi and Annexe communes, which are the largest in the city (13) and therefore more accessible to health investigators. Moreover, 66.4% of participants were married. This proportion is much higher than that reported by Guédéhoussou et al. (12) in a study on sickle cell disease prevention in Togo, where only 22% were married.

Regarding educational attainment, 49.7% of respondents had completed secondary education, while 39.2% had higher education. A large proportion were professionally active (traders, artisans, civil servants, or company employees), although 26% were unemployed. With respect to children under five years of age, most participants

had none (45.0%), followed by those with two children (24.3%). Despite the generally high level of education, respondents exhibited limited detailed knowledge of sickle cell disease.

Although 91.1% were aware of the disease, this proportion aligns with findings from Uganda (91.2%) by Tusuubira et al. (11) and Cameroon (89.8%) by Ngwengi et al. (14). However, fewer than half (45.23%) knew the cause of the disease. Poor knowledge was also observed in nearly half of respondents (47.2%) regarding clinical signs, in more than two-thirds concerning crisis-triggering factors (74.1%), and in 78.0% regarding possible complications. These findings indicate insufficient understanding of the disease, contrasting with results from a Togolese study assessing knowledge and preventive practices, where 74.8% knew the cause, 78.6% recognized the symptoms, and 57.6% were aware of crisis-triggering factors (12). Such results highlight the need to strengthen public awareness and health education, as supported by a Brazilian study emphasizing the importance of raising awareness among communities and policymakers (15).

Concerning other names for sickle cell disease, 59.17% referred to it as “SS,” 18.09% as “anemia,” and 22.74% did not know. In total, 52.32% were aware of the age of onset. Regarding disease forms, 49.63% identified the severe form and 41.08% the mild form, while others were unaware.

As for the perceived curability of the disease, 69.68% had no opinion, whereas 30.32% believed it could be cured, likely reflecting limited access to information. Among those who believed a cure was possible, 50.79% attributed it to medical treatment, while 23.02% mentioned traditional medicine—illustrating gaps in understanding. Conversely, among those who thought the disease was incurable, 59.02% justified their response by referring to its genetic nature.

Among participants familiar with the disease, a vast majority (94.75%) reported seeking modern medical care during a sickle cell crisis, considering it the most effective management approach (77.26%). Furthermore, 72.86% reported awareness of preventive measures.

Health workers were cited as the primary source of information (36.67%), contrary to findings from Ghana, where school was the main source (16), and from Uganda, where the family predominated (11). Additionally, 83.86% of respondents had encountered children living with sickle cell disease, including 5.83% who were their own. Finally, 58.60% reported identifying the disease from its clinical signs, while 41.40% relied on laboratory diagnosis.

Significant associations were found between sociodemographic variables and knowledge levels regarding sickle cell disease in Lubumbashi. Lack of education was associated with marked knowledge deficits across all domains: unschooled participants had lower probability of having heard of sickle cell disease (RR = 0.72; 95% CI [0.58-0.89], $p < 0.001$), knowing its causes (RR = 0.81; 95% CI [0.65-1.01], $p = 0.004$), and adopting adequate preventive behaviors (RR = 0.75; 95% CI [0.61-0.91], $p = 0.002$). This situation, frequently reported in sub-Saharan Africa, reflects limited access of less educated populations to reliable information sources, consistent with Mukinayi PM et al (9), advocating for targeted educational interventions.

Married participants also showed better knowledge of disease causes (RR = 1.28; 95% CI [1.08-1.52], $p = 0.017$) and more frequently adopted appropriate preventive practices (RR = 1.22; 95% CI [1.02-1.46], $p = 0.031$) than single, widowed, or divorced individuals. This could be explained by conjugal and family interactions facilitating

health information circulation, similar to Laghdaf Sidi M et al. (17), who recommend systematic premarital counseling.

Finally, participants aged 30 years and older showed more adequate preventive practices than younger ones (RR = 1.25; 95% CI [1.01-1.55], p = 0.041). This suggests maturity and life experience favor better risk perception and preventive behavior adoption, consistent with Piel FB et al (18) recommendations for strengthening youth sensitization.

Our results show sickle cell disease remains poorly known (19) despite DRC having the second highest incidence in Africa after Nigeria. We believe these findings can support establishing an information and education program for the Congolese population to combat sickle cell disease (12).

5. CONCLUSION

This study revealed that although most participants had heard of sickle cell disease, their knowledge remains limited despite its high incidence in the Democratic Republic of Congo. These results underscore the urgent need to implement a structured communication, education, and information program to effectively sensitize the Congolese population and strengthen the fight against this pathology.

Study limitations: Several limitations should be considered when interpreting these cross-sectional study results: social desirability bias (self-reporting), selection bias (community recruitment), inability to infer causality (cross-sectional design), limited generalizability to Lubumbashi (urban setting), and lack of triangulation (no direct practice verification).

Conflicts of interest

The authors declare no conflicts of interest.

Authors' contributions

All authors contributed to study conception and implementation. Material preparation, data collection, and analysis were performed by TKE, KIE, and BEM. The first draft of the manuscript was written by TKE, SPM, KLC, and NBV, and all authors commented on previous versions. All authors read and approved the final manuscript.

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