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Assessment of healthcare workers' knowledge and availability of resources for sickle cell disease management in Bukavu, Democratic Republic of the Congo

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Abstract

Introduction Sickle cell disease (SCD) is a global public health priority due to its high morbidity and mortality. In the Democratic Republic of the Congo (DRC), effective care for this disease depends on the availability of resources and the level of knowledge of healthcare workers (HCWs). However, in Bukavu, there is limited data available on these two crucial aspects, which are vital for enhancing the care of patients with SCD. This study aims to assess the availability of SCD services and the level of knowledge of HCWs in Bukavu, DRC.

Methods A cross-sectional study based on healthcare facilities (HCFs) was carried out between March and May 2024 among 501 nurses and clinicians from 58 HCFs in Bukavu. Data were collected using a structured questionnaire with 13 knowledge questions (score >7 corresponding to good knowledge) and a checklist of available resources. Pearson's $\chi 2$ test was used to assess the association between knowledge level and participant characteristics. Multivariate logistic regression was performed to determine the factors influencing knowledge.

Results Of the 501 participants, only 16.4% demonstrated good knowledge of SCD. Physicians were 8.4 times more likely to possess good knowledge compared to nurses (adjusted OR = 8.4; 95% CI: 4.5 - 15.9; $p<0.0001$). Age, clinical experience, type of HCF, attendance of SCD training, and previous management of SCD patients did not show a significant association with knowledge after adjusting for other variables ($p>0.05$). Regarding resources, 55.2% of HCFs had a falciform test, but none had advanced technologies such as isoelectrofocusing or high-performance liquid chromatography.

Conclusion This study reveals a general lack of knowledge among HCWs about SCD in Bukavu, as well as limited availability of resources for diagnosis and treatment. It is essential to improve the training of HCWs and to strengthen HCFs in order to optimize the management of SCD patients in Bukavu.

Keywords Sickle Cell Disease, Healthcare Workers, Knowledge Assessment, Resource Availability, Bukavu, Democratic Republic of the Congo

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Introduction

Sickle cell disease (SCD), also known as sickle cell anemia, is an inherited genetic disorder that primarily affects the red blood cells. The disease is characterized by a deformation of the red blood cells, which take on a sickle shape [1]. SCD is widespread in low- and middle-income countries (LMICs), particularly in the Democratic Republic of the Congo (DRC), one of the three African countries most severely affected by the disease. Each year, between 30,000 and 40,000 newborns in the DRC are born with the hemoglobin S (HbS) trait, representing a significant burden on the population [2, 3]. The disease severely impacts the daily lives of many individuals, with a substantial number unable to lead regular lives due to its complications. Studies have demonstrated that SCD significantly reduces life expectancy, particularly in LMICs. Complications associated with the disease, such as painful seizures, infections, and heart problems, can lead to premature death if not properly treated. Mortality associated with SCD in LMICs remains alarmingly high, accounting for 6.4% of under-five deaths in Africa. Tragically, 50–80% of infants born with SCD in the region do not survive beyond their fifth birthday. Globally, SCD caused 38,403 deaths in 2019, reflecting a 26% increase since 2000 [4, 5]. In the DRC, the mortality rate associated with SCD is particularly high, with 15.3% (95% confidence interval (95% CI): 13.3–17.3) of children under 1 year, 36.4% (95% CI: 33.4–39.4) of those under 5 years, and 43.3% (95% CI: 39.3–47.3) of those under 10 years succumbing to the disease [6]. This high mortality rate is driven by various factors, including limited access to healthcare, lack of adequate medical resources, and the socio-economic challenges faced by the population [7].

The knowledge of healthcare workers (HCWs) and the availability of resources are critical elements in the management of SCD, a major public health challenge in the DRC. Studies have consistently shown that healthcare professionals have little knowledge of SCD, which is compounded by inadequate resources for effective care [8, 10]. In Bukavu, a city in eastern DRC, the situation reflects the broader challenges facing the country, where limited access to health and social support exacerbates the difficulties of SCD management [3, 11]. Interestingly, while university students in the DRC are generally aware of cardiovascular disease, they have little understanding of the hereditary nature of SCD and its preventive measures [12]. This indicates a potential area for educational interventions. Additionally, the high prevalence of SCD and sickle cell trait in the north-eastern region of the DRC highlights the need to improve health services and transfusion safety to effectively manage the disease [13–15]. Both children and adults with SCD require specialized and primary care services throughout their lives. A wide range of specialized services is needed, including multidisciplinary expert providers. Access to quality healthcare services for the diagnosis and treatment of SCD is essential to improve the lives of people affected by this disease. However, in many LMICs, such as the DRC, the availability of these resources remains a major challenge. HCWs' insufficient knowledge of SCD and the limited availability of resources for care are shortcomings contributing to the difficulties encountered in providing adequate care for SCD patients. In this study, the aim is to assess the current state of availability and quality of healthcare services for SCD, as well as the level of knowledge of HCWs in Bukavu. We will examine the resources available in healthcare facilities (HCFs), such as referral health centers, general referral hospitals, and private clinics, as well as the diagnostic and treatment protocols implemented. We will propose recommendations and interventions to improve the accessibility and quality of health services in this area. This study is of vital importance in guiding public health policies to improve the management of SCD in Bukavu and similar areas.

Materials and methods

Study setting and design

This cross-sectional study was conducted from March to May 2024 in 58 HCFs in Bukavu, South Kivu Province, DRC. These HCFs consist of public (n=20) and private (n=38) institutions that offer outpatient and inpatient SCD services to the majority of SCD patients in the city. All of these HCFs included in the study operate outpatient clinics specifically for children and adults with SCD, overseen by doctors and nurses. Additionally, specialized pediatricians, in-house physicians, and hematologists are involved in patient care whenever possible. Upon admission, patients receive treatment in general pediatrics, internal medicine, general surgery, or other appropriate wards.

Study participants

For the purposes of this study, HCWs, including doctors and nurses from 58 HCFs in Bukavu, were deemed eligible and were randomly selected. The randomization process was applied to the healthcare workers themselves, who were selected from a list of eligible HCWs across various HCFs.

HCFs were selected inclusively based on a list available from the Provincial Health Division of South Kivu and had to meet specific criteria to ensure quality and relevance. These criteria included having at least three permanent general practitioners, 10 nurses, and one laboratory technician; a minimum capacity of 25 beds for inpatient care; and a laboratory capable of conducting tests for SCD. The total of 58 HCFs included in this study

represents 100% of all HCFs in Bukavu, ensuring comprehensive coverage of diverse healthcare settings.

The exclusion criteria for HCWs were being on vacation or absent from work on the day of data collection or working in a HCF not selected for the study. For HCWs who were absent during the survey period, efforts were made to contact and include them if they returned within the data collection timeframe. The study covered referral health centers, general referral or university hospitals, and private clinics. HCWs, including doctors and nurses who provide services and interact directly with patients seeking medical services for SCD in the selected HCFs, were eligible to participate in this study.

Sample size

Cochran's formula was utilized to determine the sample size ($n = z^2pq/d^2$), with a 95% confidence interval standard deviation (1.96), an estimated prevalence of 46% of HCWs with good SCD knowledge [10], and a precision error of 5%. The minimum sample size calculated was 382 participants. Assuming a non-response rate of 20%, a sample size of 458 was determined; however, 501 participants were ultimately recruited for the study.

Participants were selected using a multi-stage sampling method. Firstly, the HCFs involved were selected. In the second phase, the number of participants (doctors and nurses) to be included from each HCF was determined in proportion to the total number of staff in each HCF. Finally, individual participants were recruited consecutively from each HCF, selecting each available HCW meeting the inclusion criteria until the desired sample size was reached.

Study variables

The dependent variables related to the overall level of SCD knowledge of HCWs, as well as the availability of the means necessary for the diagnosis and treatment of this disease within the HCF. Independent variables included age (in years), gender (male or female), number of years of clinical experience (in years), type of HCF (general referral hospital/university hospital, private clinic, or referral health center), medical title (nurse or doctor), short-term training in SCD in the last year (yes or no), and having treated a SCD patient in the last month (Supplementary file 1).

Data on the resources available in the HCF were collected using an inventory checklist, which included the following variables: type of HCF (general referral hospital/university hospital, private clinic, or referral health center), sector of activity (private or public), diagnostic equipment for SCD, other laboratory investigations, clinical tests at the point of care, medical imaging, analgesics and painkillers, antibiotics and antimalarials, hydroxyurea, folic acid, infusion fluids, blood transfusion and exchange transfusion, and emergency surgery and intensive care services (Supplementary file 2).

Collecting data

The selected interviewers underwent comprehensive training, which included an overview of the study context, a thorough explanation of the survey tool, and a simulation of the survey process. A total of ten interviewers were recruited. They briefed participants on the study's objectives and procedures, securing their written informed consent prior to administering the questionnaire. On average, each survey session lasted approximately 20 to 25 minutes.

Data were collected using a self-administered questionnaire that had been validated and applied in prior studies [8, 9, 16]. This instrument was tailored to align with the local context and designed to evaluate the level of knowledge of HCWs regarding SCD. The reliability of the questionnaire was assessed through the test-retest method. A preliminary test was carried out with ten HCWs to verify the clarity of the questions and the suitability of the tool for the local setting. Any unclear questions were revised, and the final version of the questionnaire was optimized to ensure consistent and accurate data collection. Thirteen questions on SCD covered knowledge of the diagnosis, the genotype of SCD, the ideal time for screening for SCD, confirmatory tests for SCD, clinical features of SCD, conditions that promote SCD in patients with SCD, and knowledge of the treatment of SCD (management of acute complications of SCD, medications used to treat pain attacks in patients with SCD, medications used to prevent and/or treat complications of SCD, indications for the use of antibiotics in SCD, indications for blood transfusion in patients with SCD, ways to prevent infections in patients with SCD as well as pregnancy, and use of contraception in patients with SCD). The questions were multiple-choice, and participants were asked to choose the best answer for each question (Supplementary file 1). The dependent variable, the score for the overall level of knowledge, was calculated by summing the correct responses to knowledge-based questions. The score ranged from 0 to 13 points, with higher scores indicating greater knowledge. The interpretation of the scores was categorized into two levels (poor or good knowledge) based on pre-defined thresholds. The validity of the instrument was ensured through content validation by local experts in SCD management and a pilot test conducted in a non-study population to confirm its clarity and reliability. Cronbach's alpha coefficient was calculated to assess internal consistency, yielding a value of 0.7201, indicating acceptable reliability.

Data on the resources available in the HCFs were obtained using an inventory checklist adapted for SCD management used by Jonathan et al. [8], indicating the minimum resources required by the level of HCF. In each HCF, a checklist was completed by interviewing the managers of the units concerned and checking the availability of drugs (antibiotics, antimalarials, analgesics, folic acid, and hydroxyurea), ensuring they were not out of date and still usable. The presence of services such as blood transfusion, exchange transfusion, emergency surgery, and intensive care unit was also assessed (Supplementary file 2). Expired drugs and out-of-service equipment were considered unavailable.

Statistical analysis

Data were checked for accuracy and consistency prior to analysis. Open-ended responses in the demographic section were first edited, then classified and coded before being entered. Participant characteristics were studied using descriptive statistics. The normality of the distribution of continuous variables, such as age and years of practice, was tested using the Shapiro-Wilk test. Since none of the variables exhibited a normal distribution, they were reported as medians with interquartile ranges (IQR), and then categorized as follows: age (20–30 years, 31–40 years, 41–50 years, and >50 years) and years of clinical experience (<5 years, 5–9 years, and >9 years). These, along with other categorical variables (gender, level of education, type of HCF, medical title, sickle cell training, and recent management of a sickle cell patient), were presented as frequencies and percentages in tabular format.

Knowledge of SCD was assessed through 13 multiple-choice questions, including 6 on diagnosis and 7 on treatment. 'One' point was awarded for each correct answer and 'zero' for an incorrect answer. To determine the overall level of knowledge about SCD, the sum of correct answers was calculated for diagnosis and treatment, with the following thresholds: a score greater than 7 (more than 54% accuracy) indicated a good level of knowledge, while a score less than or equal to 7 (54% accuracy or less) corresponded to an insufficient or poor level of knowledge [8, 9, 16].

Inferential statistical analyses were conducted to determine the factors influencing the level of knowledge about SCD. Various independent variables such as age, gender, education level, clinical experience, HCF type, medical title, SCD training, and recent management of a sickle cell patient were compared with the dependent variable (general knowledge about SCD) using the Chi-square test. A significance level of $p < 0.05$ was considered statistically significant. Subsequently, a bivariate analysis was conducted to assess the association between the overall level of knowledge and the independent variables. Only variables with a p-value ≤ 0.2 in the bivariate analysis (gender, HCF type, medical title, and recent management of a sickle cell patient) were included in a multivariate logistic regression model to account for different predictors' effects. Odds ratios (OR) were used to demonstrate the relationship between the dependent variable and associated factors, while 95% confidence intervals and p-values were utilized to determine statistical significance.

To evaluate the availability of resources for the diagnosis and management of SCD, we utilized descriptive statistics to summarize the resources present in the HCFs. These findings were expressed as frequencies and percentages, and were presented in tabular form. All statistical analyses were carried out using STATA software version 16 [17].

Ethical considerations

Ethical approval for this study was granted by the Medical Ethics Committee of the Official University of Bukavu (Approval number UOB/CEM/010/2023). Authorization to conduct the study was also sought from the Provincial Health Division of South Kivu Province (N°061/CD/DPS-SK/2024). Written informed consent was obtained from all participants prior to their participation in the study. The research was conducted in accordance with the ethical principles outlined in the Declaration of Helsinki and in accordance with the guidelines for the Ethical Review of Research Involving Human Subjects in the DRC, ensuring the protection, dignity, and confidentiality of all participants.

Results

Demographic and professional characteristics of participants

A total of 501 HCWs took part in the study, with an almost equal gender distribution: 50.7% (254/501) were men and 49.3% (247/501) were women. Participants ranged in age from 20 to 62, with a median age of 32 [IQR: 28 – 42], with the majority in the 20 – 30 age group at 43.5% (218/501). The majority of participants were nurses, representing 67.1% (336/501), while 32.9% (165/501) were doctors.

In relation to HCF, 35.9% (180/501) were employed in private clinics, 33.1% (166/501) in referral health centers, and 30.9% (155/501) in general referral hospitals. Regarding clinical experience, 38.3% (192/501) had less than 5 years of experience, 25.2% (126/501) had between 5 and 9 years, and 36.5% (183/501) had over 9 years of experience.

With respect to SCD training, 20.6% (103/501) of participants had received specific training, while 79.4%

(398/501) had not. Moreover, 74.3% (372/501) of participants had managed a SCD patient in the preceding month (Table 1).

General level of knowledge about sickle cell disease among study participants

Only 16.4% (82/501) of HCWs demonstrated a good level of knowledge about SCD, with a 95% confidence interval ranging from 13.4% to 19.9%.

Table 2 illustrates that doctors exhibit a higher overall knowledge of SCD compared to nurses, with notable variances in areas like manifestations of SCD, vasoocclusion, and factors favoring SCD ($p < 0.0001$). Nevertheless, topics such as antibiotic use and reproductive health displayed no significant difference between the two groups.

Regression analysis of factors influencing knowledge about sickle cell disease among healthcare workers.

When examining the association between the overall level of knowledge and participant characteristics, it was determined that gender, type of HCF, medical title, and recent interaction with a SCD patient were significantly correlated with the level of knowledge about SCD. Table 3 summarizes the results of the bivariate and multivariate logistic regression analyses. The final model revealed that only one factor was significantly associated with the level of knowledge about SCD. Doctors were significantly more likely to have good SCD knowledge than nurses (adjusted OR = 8.4; 95% CI: 4.5 - 15.9; $p < 0.0001$). In contrast, neither age nor gender showed a significant association with SCD knowledge after adjustment for other variables. Working in a general referral hospital or a private clinic did not significantly increase the odds of having good SCD knowledge compared to those working in a referral health center, after adjustment (adjusted OR

Table 1 Demographic and professional characteristics and general level of knowledge of sickle cell disease among healthcare workers in Bukavu ($N = 501$)

Variable	Total (N=501), *n (%)*	Knowledge		p-value
		Good (n=82), *n (%)*	Poor (n=419), *n (%)*	
Age				0.0688
20–30 years	218 (43.5)	26 (11.9)	192 (88.1)	
31–40 years	151 (30.1)	30 (19.9)	121 (80.1)	
41–50 years	89 (17.8)	20 (22.5)	69 (77.5)	
> 50 years	43 (8.6)	6 (13.9)	37 (86.1)	
Gender				0.0118
Male	254 (50.7)	52 (20.5)	202 (79.5)	
Female	247 (49.3)	30 (12.2)	217 (87.8)	
Type of healthcare facility				0.0320
Referral health center	166 (33.1)	17 (10.2)	149 (89.8)	
Private clinic	180 (35.9)	34 (18.9)	146 (81.1)	
General referral hospital/University hospital	155 (30.9)	31 (20.0)	124 (80.0)	
Medical title				<0.0001
Doctor	165 (32.9)	63 (38.2)	102 (61.8)	
Nurse	336 (67.1)	19 (5.6)	317 (94.4)	
Clinical experience				0.8078
< 5 years	192 (38.3)	34 (17.7)	158 (82.3)	
5–9 years	126 (25.2)	20 (15.9)	106 (84.1)	
> 9 years	183 (36.5)	28 (15.3)	155 (84.7)	
Have you received training on sickle cell disease in the last year?				0.1245
No	398 (79.4)	60 (15.1)	338 (84.9)	
Yes	103 (20.6)	22 (21.4)	81 (78.6)	
Have you treated a sickle cell patient in the last month?				0.0008
No	129 (25.8)	9 (7.0)	120 (93.0)	
Yes	372 (74.3)	73 (19.6)	299 (80.4)	

Table 2 Percentages of respondents with correct answers to questions on various sickle cell disease topics

Topics of questions asked	Doctor (*n*=165), *n(%)*	Nurse (*n*= 336), *n(%)*	Total *N*=501, *n(%)*	*p*-value
Neonatal Screening Program	114 (69.1)	210 (62.5)	324 (64.7)	0.1469
Sickle Cell Condition	124 (75.2)	179 (53.3)	303 (60.5)	<0.0001
Sickle Cell Anemia Genotype	140 (84.9)	272 (80.9)	412 (82.2)	0.2836
Sickle Cell Trait	14 (8.5)	22 (6.6)	36 (7.2)	0.4301
Sickle cell disease manifestations	56 (33.9)	57 (17.0)	113 (22.6)	<0.0001
Vaso-occlusion	114 (69.1)	145 (43.2)	259 (51.7)	<0.0001
Factors that favor red blood cells sickling	93 (56.4)	66 (19.6)	159 (31.7)	<0.0001
Warning Signs	13 (7.9)	13 (3.9)	26 (5.2)	0.0572
Medications used in prevention and/or treatment of sickle cell disease	67 (40.6)	46 (13.7)	113 (22.6)	<0.0001
Use of antibiotics	51 (30.9)	84 (25.0)	135 (27.0)	0.1612
Adolescent Health	61 (37.0)	56 (16.7)	117 (23.4)	<0.0001
Pregnancy and contraception	30 (18.2)	57 (17.0)	87 (17.4)	0.7353
Care for prevention of leg ulcers	95 (57.6)	140 (41.7)	235 (46.9)	0.0011

Table 3: Regression analysis of factors influencing healthcare worker knowledge

Variable	Bivariate analysis		Multivariate analysis	
	Crude odds ratio [95% confidence interval]	*p*-value	Adjusted odds ratio [95% confidence interval]	*p*-value
Age				
20–30 years	0.8 [0.3 - 2.2]	0.908	0.2 [0.1 - 1.0]	0.053
31–40 years	1.5 [0.6 - 3.9]	0.511	0.6 [0.2 - 2.1]	0.411
41–50 years	1.8 [0.7 - 4.8]	0.358	1.0 [0.3 - 3.2]	0.964
> 50 years	Reference		Reference	
Gender				
Male	1.9 [1.1 - 3.0]	0.016	1.2 [0.7 - 2.1]	0.533
Female	Reference		Reference	
Type of healthcare facility				
Referral health center	Reference		Reference	
Private clinic	2.0 [1.1 - 3.8]	0.034	1.3 [0.6 - 2.7]	0.454
General referral hospital	2.2 [1.2 - 4.1]	0.022	1.0 [0.5 - 2.2]	0.934
Medical title				
Doctor	10.3 [5.9 - 18.0]	<0.0001	8.4 [4.5 - 15.9]	<0.0001
Nurse	Reference		Reference	
Clinical experience				
< 5 years	1.2 [0.7 - 2.1]	0.625	2.2 [0.8 - 6.2]	0.130
5–9 years	1.0 [0.6 - 2.0]	1.000	1.3 [0.5 - 3.1]	0.578
> 9 years	Reference		Reference	
Have you received training on sickle cell disease in the last year?				
No	Reference		Reference	
Yes	0.6 [0.4 - 1.1]	0.165	1.8 [0.8 - 4.1]	0.174
Have you treated a sickle cell patient in the last month?				
No	Reference		Reference	
Yes	3.3 [1.6 - 6.7]	0.001	0.9 [0.5 - 1.8]	0.844

= 1.0; 95% CI: 0.5 - 2.2; $p = 0.934$ and adjusted OR = 1.3; 95% CI: 0.6 - 2.7; $p = 0.454$ respectively).

Furthermore, receiving a SCD patient in the previous month was not significantly associated with improved knowledge after adjustment (adjusted OR = 0.9; 95% CI: 0.5 - 1.8; $p = 0.844$), despite showing a significant association in the bivariate analysis. Clinical experience, while significant in the bivariate analysis, did not have a significant association after adjustment.

Resources available for the diagnosis and treatment of sickle cell disease

Table 4 shows the resources available in private and public HCFs in Bukavu for the diagnosis and management of SCD. Among specific diagnostic equipment, the falciformation test is the most widely available, present in 55.2% of HCFs, although no hospital has isoelectrofocalisation or high-performance liquid chromatography. Hemoglobin electrophoresis, an important test for the diagnosis of SCD, is available in only 5.2% of HCFs, mainly in public hospitals.

When it comes to laboratory investigations, basic tests like peripheral blood smears (60.3%) and rapid HIV tests (98.3%) are easily accessible. However, more advanced equipment such as hematology analyzers or polymerase chain reaction (PCR) machines are only available in less than 50% of HCFs. Intensive care and emergency surgery equipment, along with blood transfusion services, are also lacking, present in only 32.8% and 5.2% of HCFs, respectively.

A comparison of available resources between the private and public sectors reveals significant differences. For instance, the falciform test is more frequently available in the private sector (57.9%) than in the public sector (50.0%). Conversely, hemoglobin electrophoresis is more common in public hospitals (10%) than in private HCFs (2.6%). Public HCFs also have a higher presence of PCR equipment (15.0% vs. 5.3% in the private sector) and intensive care units (45.0% vs. 26.3% in the private sector). The private sector is less equipped for basic care, with lower availability of digital oximeters (65.8% in the private sector versus 75.0% in the public sector). In terms of medicines, both sectors have nearly complete availability of essential analgesics such as paracetamol and ibuprofen (100% in both sectors), as well as antibiotics like penicillin V (94.7% in the private sector and 95.0% in the public sector) and metronidazole (100% in both sectors). However, specific treatments show disparities: morphine is more accessible in the private sector (42.1% versus 30.0% in the public sector), while ceftriaxone availability is higher in the public sector (90.0% versus 73.7% in the private sector). Similarly, pethidine is less available in both sectors, with 34.2% in the private sector and 20.0% in the public sector.

Discussion

This study assessed HCWs' SCD knowledge. As pointed out by Gomes et al. [18], the HCWs' level of SCD knowledge has an indirect but significant impact on the quality of care they provide to patients.

The study reveals that only a small proportion of HCWs (16.4%) are familiar with SCD. Yet the DRC is the second most affected country in Africa after Nigeria, with an estimated prevalence of 2% among newborns [13, 15]. In some regions, such as Lubumbashi, this prevalence may even reach 5.0% to 7.1% [14, 19]. We would therefore expect more HCW to be well-informed about SCD and neonatal screening. Several studies elsewhere have also revealed a low level of knowledge among doctors and nurses regarding SCD [20–25]. Comparing our results with other studies, it appears that our rate is lower than that reported by Jonathan et al. [8] in Dar es Salaam (Tanzania), where 25.1% of HCW had a good SCD knowledge. This difference could be attributed to a variety of factors, including access to continuing education programs and awareness initiatives, which may be more developed in the Tanzanian context. On the other hand, the results of our study are superior to those reported by Katamea et al. [9] in Lubumbashi (DRC), where only 7.9% of respondents had a good SCD knowledge. This extremely low prevalence may be explained by major shortcomings in the training of HCWs in certain regions of the country, particularly in terms of awareness of the disease and neonatal screening. Although our study shows a slight improvement on that of Katamea et al. [9], it nevertheless highlights the urgent need to improve training and knowledge of SCD among HCWs in the DRC, given the major impact of this disease on public health in this country. In sum, although our prevalence of good knowledge is higher than that reported in Lubumbashi [9], it remains inadequate by the standards observed in Brazil [26], highlighting the need to strengthen educational and awareness programs among HCWs in the DRC to improve the management of patients with SCD. These low levels of knowledge are a cause for concern, as good mastery of SCD by HCWs is crucial to ensure early neonatal screening and rapid access to comprehensive care, which has been shown to be effective in reducing morbidity and mortality in high-income countries [27].

The present study revealed a strong association between medical title and the level of knowledge about SCD among HCWs in Bukavu. Specifically, doctors had a significantly higher probability of having a good SCD knowledge compared to nurses (adjusted OR = 8.4; 95% CI: 4.5 - 15.9; $p < 0.0001$). These results are consistent

Table 4 Resources available in Bukavu health facilities (*N*=58)

Resource category	Items	Private sector (*n*=38)	Public sector (*n*=20)	Total (*N*=58)
	Falciform test	22 (57.9%)	10 (50.0%)	32 (55.2%)
Diagnostic equipment for sickle cell disease	Isoelectrofocusing	0 (0.0%)	0 (0.0%)	0 (0.0%)
	Hemoglobin electrophoresis	1 (2.6%)	2 (10.0%)	3 (5.2%)
	High-performance liquid chromatography	0 (0.0%)	0 (0.0%)	0 (0.0%)
	Rapid diagnostic test (SickleSCAN® or HemoTypeSC®)	9 (23.7%)	9 (45.0%)	18 (31.0%)
Other laboratory investigations	Hematology analyzer	16 (42.1%)	10 (50.0%)	26 (44.8%)
	Peripheral blood smear	24 (63.2%)	11 (55.0%)	35 (60.3%)
	Blood culture	6 (15.8%)	4 (20.0%)	10 (17.2%)
	Urine culture	9 (23.7%)	5 (25.0%)	14 (24.1%)
	Malaria rapid diagnostic test	36 (94.7%)	19 (95.0%)	55 (94.8%)
	Rapid HIV test	37 (97.4%)	20 (100.0%)	57 (98.3%)
	Blood grouping and cross-matching	32 (84.2%)	17 (85.0%)	49 (84.5%)
	Polymerase chain reaction (PCR) machine	2 (5.3%)	3 (15.0%)	5 (8.6%)
	Erythrocyte sedimentation rate	31 (81.6%)	16 (80.0%)	47 (81.0%)
Clinical tests at the point of care	Tensiometer	36 (94.7%)	20 (100.0%)	56 (96.6%)
	Stethoscope	36 (94.7%)	20 (100.0%)	56 (96.6%)
	Scale	35 (92.1%)	20 (100.0%)	55 (94.8%)
	Thermometer	38 (100.0%)	19 (95.0%)	57 (98.3%)
	Digital oximeter	25 (65.8%)	15 (75.0%)	40 (69.0%)
	Oxygen apparatus	22 (57.9%)	11 (55.0%)	33 (56.9%)
	Hemocue device	10 (26.3%)	12 (60.0%)	22 (37.9%)
	Measuring tape	37 (97.4%)	20 (100.0%)	57 (98.3%)
	Urine strips	30 (79.0%)	17 (85.0%)	47 (81.0%)
Medical imaging	Ultrasound	21 (55.3%)	12 (60.0%)	33 (56.9%)
	Electrocardiogram (ECG)	15 (39.5%)	8 (40.0%)	23 (39.7%)
	Echocardiogram	5 (13.2%)	3 (15.0%)	8 (13.8%)
	Transcranial Doppler	4 (10.5%)	1 (5.0%)	5 (8.6%)
	Radiography	7 (18.4%)	7 (35.0%)	14 (24.1%)
	Computed tomography (CT scan)	1 (2.6%)	2 (10.0%)	3 (5.2%)
	Magnetic resonance imaging	1 (2.6%)	1 (5.0%)	2 (3.5%)
Analgesics and painkillers	Paracetamol	38 (100.0%)	20 (100.0%)	58 (100.0%)
	Ibuprofen	38 (100.0%)	20 (100.0%)	58 (100.0%)
	Diclofenac	36 (94.7%)	20 (100.0%)	56 (96.6%)
	Pethidine	13 (34.2%)	4 (20.0%)	17 (29.3%)
	Morphine	16 (42.1%)	6 (30.0%)	22 (37.9%)
Antibiotics and antimalarials	Penicillin V	36 (94.7%)	19 (95.0%)	55 (94.8%)
	Amoxiclav	28 (73.7%)	16 (80.0%)	44 (75.9%)
	Ceftriaxone	28 (73.7%)	18 (90.0%)	46 (79.3%)
	Metronidazole	38 (100.0%)	20 (100.0%)	58 (100.0%)
	Gentamycin	36 (94.7%)	20 (100.0%)	56 (96.6%)
	Artemether lumefantrine	38 (100.0%)	20 (100.0%)	58 (100.0%)
Hydroxyurea		3 (7,9%)	2 (10.0%)	5 (8.6%)
Folic acid		36 (94,7%)	20 (100.0%)	56 (96.6%)
Infusion fluids	Saline solution	37 (97.4%)	19 (95.0%)	56 (96.6%)
	Ringer lactate	37 (97.4%)	19 (95.0%)	56 (96.6%)
Blood transfusion and exchange transfusion	Blood transfusion	23 (60.5%)	14 (70.0%)	37 (63.8%)
	Exchange transfusion	1 (2.6%)	2 (10.0%)	3 (5.2%)
Emergency surgery and intensive care services	Emergency surgery capacity	23 (60.5%)	14 (70.0%)	37 (63.8%)
	Intensive care unit	10 (26.3%)	9 (45.0%)	19 (32.8%)

with those of other studies [9, 10], which demonstrated that SCD knowledge was significantly more widespread among doctors than among nurses. This difference may be attributed to the more comprehensive coverage of SCD in training programs for doctors compared to those for nurses, where this disease is often given less emphasis [8, 9, 25, 28].

In contrast to the findings by Jonathan et al. [8] and Mukinayi Mbiya et al. [10], which indicated that years of clinical experience positively influenced the level of knowledge about SCD, our study found no significant relationship between years of practice and knowledge after adjustment. This lack of association could be attributed to the absence of specific and structured continuing education programs on SCD, regardless of the duration of practice. In our settings, healthcare workers often rely on their initial training, which typically provides limited exposure to specialized topics like SCD, especially in regions where resources for ongoing education are scarce. Without structured and targeted professional development opportunities, knowledge gaps and stagnation may persist, even among those with years of clinical experience. Previous studies have emphasized the crucial role of continuous, disease-specific education in improving healthcare workers' competencies and knowledge, particularly in managing chronic conditions like SCD [29]. To address these gaps effectively, future initiatives should prioritize integrating SCD-focused content into regular continuing education programs. Ensuring HCWs have access to relevant, up-to-date training will be essential for improving patient care outcomes and adapting to the evolving challenges in healthcare practice.

Similarly, the age and sex of the participants showed no significant influence on the level of knowledge, which also corroborates the results observed in other studies, where these variables were not associated with the level of SCD knowledge [8, 9].

It is also noteworthy that working in a referral hospital or private clinic did not significantly enhance the likelihood of having a good SCD knowledge compared to those working in healthcare centers. This finding may be elucidated by the similar resources and training available in the various types of HCFs in Bukavu, which differs from other settings where higher-level hospitals have superior infrastructures and provide more training opportunities.

Although in our bivariate analysis, having managed an SCD patient in the previous month seemed to be associated with better knowledge, this association was not confirmed after adjustment, consistent with the results of Jonathan et al. [9], who also emphasized the insufficient coverage of SCD in continuing education programs. These findings underscore the necessity of enhancing SCD-specific training programs to enhance the quality of patient care, regardless of professional setting or clinical experience.

The present study indicates that 79.4% of HCWs stated that they had not attended a training session on SCD. This result is similar to those observed in other studies [24], which found that a large proportion of HCWs (75 to 94.2%) had not received specific training on SCD. This observation underlines the crucial and immediate importance of reinforcing the ongoing training of HCWs in all aspects related to SCD. It is essential to target the specific responsibilities of each HCW in order to promote early diagnosis and optimize care, with the aim of significantly improving the quality of life of SCD patients.

This study revealed a lack of adequate information on SCD among doctors and nurses in our region. It is the responsibility of health authorities to ensure ongoing training, as well as regular updating of the skills and knowledge of these HCWs throughout their careers [30]. For optimal results, it is essential that HCWs benefit from a constant and effective training and information program, in order to meet the evolving challenges of SCD management.

To ensure effective clinical outcomes in the management of SCD, it is crucial for adequate resources to be available in HCFs catering to both inpatients and outpatients [31]. Our study's findings revealed significant resource gaps across both private and public HCFs in the diagnosis and treatment of SCD. For example, crucial confirmatory diagnostic tests such as hemoglobin electrophoresis, isoelectric focusing, and high-performance liquid chromatography were nearly non-existent in the surveyed HCFs. Additionally, advanced imaging tools like transcranial Doppler, scanners, and MRI machines were largely unavailable in over 90% of HCFs. Moreover, critical care resources such as intensive care units (32.8%), the capacity for exchange transfusions (5.2%), and essential medications like hydroxyurea (8.6%) were severely limited in these hospitals. To better illustrate the availability of diagnostic tools and resources, Table 4 provides a breakdown of resource availability by HCF. This level of detail highlights disparities, as larger institutions like general or university hospitals are generally better equipped compared to smaller private clinics or health centers. For instance, intensive care units were predominantly found in general referral hospitals (100%) and university hospitals (100%), while smaller HCFs had little to no capacity for critical care interventions.

These resource shortfalls may partly explain the delays in diagnosis and adverse health outcomes associated with SCD in the DRC. The absence of confirmatory tests for SCD in Bukavu hospitals mirrors similar problems encountered in other DRC cities, such as Kinshasa, where

65% of doctors report difficulties in performing hemoglobin electrophoresis due to a lack of suitable equipment [11]. Although our study showed that the falciformation test was available in 55.2% of HCFs, this examination remains insufficient for an accurate diagnosis, as it cannot differentiate between homozygous (Hb SS) and heterozygous (Hb AS) forms, a problem also found in other African countries [9].

The lack of medical imaging equipment, such as scanners and MRIs, in hospitals corresponds to a common situation in resource-limited countries, where these technologies, indispensable for diagnosing serious complications such as strokes, are often absent [8, 32]. In contrast, basic equipment such as blood pressure monitors, stethoscopes, thermometers, pulse oximeters and urine dipsticks were widely available, enabling at least an initial clinical assessment of patients during routine consultations [26]. However, to optimize the management of SCD patients, it is essential to increase the availability of advanced diagnostic tools and guarantee access to specific treatments such as hydroxyurea in all the region's HCFs.

SCD contributes to anemia in children under five in the DRC. Severe anemia associated with SCD is a life-threatening emergency requiring rapid blood transfusion. Our study revealed that blood transfusion services were available in 63.8% of the HCFs surveyed, with better availability in the public sector (70.0%) than in the private sector (60.5%). However, the capacity to perform exchange transfusions was clearly insufficient, being available in only 5.2% of HCFs, with a slight superiority in the public sector (10.0%) over the private sector (2.6%). It is crucial to develop these capacities, necessary to treat serious emergencies such as acute chest syndrome, in specialized referral centers [8, 33].

Comprehensive management of SCD includes treatment of vasoocclusive crises, as well as prevention and prompt treatment of bacterial infections, malaria, and severe anemia. This study showed that drugs such as folic acid (available in 96.6% of HCFs), antibiotics (such as penicillin V available in 94.8% of HCFs, gentamycin in 96.6%, and amoxicillin + clavulanic acid in 75.9%), antimalarials (such as artemether-lumefantrine, available in 100% of HCFs), and analgesics (paracetamol in 100%, ibuprofen in 100%, diclofenac in 96.6%, and morphine in 37.9%) were widely available in both sectors. However, hydroxyurea, an essential drug in the management of SCD, was available in only 8.6% of HCFs, with slightly higher availability in the public sector (10.0%) than in the private sector (7.9%). Although the availability of most essential medicines is encouraging, it is worrying that hydroxyurea is not accessible in the majority of HCF. It is, therefore, imperative to increase the availability of this drug not only in public hospitals but also in private ones, where its absence considerably limits therapeutic options for SCD patients. Expanding access to hydroxyurea would not only improve symptom control and prevent serious complications but also reduce repeat hospitalizations and improve patients' quality of life. This expansion would require increased awareness among HCWs of the benefits of this treatment, as well as a strong commitment from health authorities and international partners to ensure a regular and affordable supply to HCFs, particularly in resource-limited areas.

This study has several limitations that should be considered when interpreting the findings. First, the cross-sectional design limits the ability to establish causal relationships between HCWs' knowledge levels and the quality of care provided to patients with SCD. Longitudinal studies would be necessary to assess the impact of improved knowledge on patient outcomes over time. Second, the data on HCWs' knowledge were self-reported through questionnaires, which may introduce social desirability bias, as participants might have overestimated their knowledge or provided responses they believed were expected. Third, the study was conducted in HCFs within Bukavu, South Kivu Province, and may not be generalizable to other regions in the DRC or similar resource-limited settings. Differences in healthcare infrastructure, training opportunities, and resource availability could affect the applicability of these findings. Additionally, the assessment of resource availability was based on direct observation and interviews with unit managers, which may not fully reflect actual resource utilization in daily clinical practice, particularly during periods of temporary shortages or equipment failure. The study also did not account for several contextual factors, such as financial constraints, organizational barriers, or the motivation and workload of healthcare staff, all of which may influence HCWs' knowledge and resource availability. Furthermore, while this study highlights gaps in knowledge and resources, it does not evaluate other critical aspects of SCD care, such as patient adherence to treatment, the effectiveness of management protocols, or patient satisfaction with healthcare services. Despite these limitations, the findings provide valuable insights into the challenges of SCD care in Bukavu and emphasize the urgent need for targeted interventions to improve HCWs' knowledge and resource availability. Future research should address these limitations by incorporating longitudinal designs, exploring broader regions, and examining additional factors that influence the management of SCD.

Conclusion

This study highlights significant gaps in HCWs' knowledge of SCD and limited access to essential diagnostic tools and treatments in Bukavu's HCFs. While doctors showed better knowledge than nurses, overall awareness remains inadequate, emphasizing the need for continuous training. The scarcity of advanced diagnostics like hemoglobin electrophoresis and treatments such as hydroxyurea hampers effective SCD management. Addressing these challenges requires strengthening healthcare infrastructure, improving staff capacity, and fostering collaboration among local authorities, HCFs, and international partners to enhance SCD care in resource-limited settings.

Abbreviations

95% CI	95% confidence interval
DRC	Democratic Republic of the Congo
Hb	Hemoglobin
HCF	Healthcare facility
HCW	Healthcare worker
IQR	Interquartile range
LMICs	Low- and middle-income countries
OR	Odds ratio
PCR	Polymerase chain reaction
SCD	Sickle cell disease
SSA	Sub-Saharan Africa

Supplementary Information

The online version contains supplementary material available at https://doi.org/10.1186/s12913-025-12330-7.

Supplementary file 1. Knowledge Assessment Questionnaire on Sickle Cell Disease Among Healthcare Workers in Bukavu, Democratic Republic of the Congo.

Supplementary file 2. Resources Availability Questionnaire.

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Not applicable.

Authors' contributions

N.M.N., O.M., A.K.M., and S.O.W. conceptualized the study and designed the methodology; N.M.N., O.M. and Y.M.K. developed the software; N.M.N., V.B.F., and T.B.K. conducted the validation. O.M., T.B.K., and S.O.W. performed formal analysis; N.M.N., V.B.F., and Y.M.K. collected the data; N.M.N., O.M., Y.M.K., V.B.F., and T.B.K. prepared the original draft of the manuscript; A.K.M. and S.O.W. provided supervision and contributed to the review and editing. All authors reviewed and approved the final version of the manuscript for publication.

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Data availability

The datasets used and/or analyzed during the current study are available from the corresponding author on reasonable request.

Declarations

Ethics approval and consent to participate

Ethical approval for this study was obtained from the Medical Ethics Committee of the Official University of Bukavu (Approval No. UOB/CEM/010/2022). Written informed consent was obtained from each participant with an assurance of confidentiality of information and the right to withdraw from the study at any time. The research was conducted in accordance with the ethical principles outlined in the Declaration of Helsinki and in accordance with the guidelines for the Ethical Review of Research Involving Human Subjects in the Democratic Republic of the Congo (DRC), ensuring the protection, dignity, and confidentiality of all participants.

Consent for publication

Not applicable

Competing interests

The authors declare no competing interests.

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