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Original article

Assessment of Diagnostic and Clinical Facilities for Sickle Cell Disease at the National Institute of Oncology, Sabratha, Libya

Haleemah Abdulrahman, Ali Madour*

Department of Molecular Biology and Biochemistry, Faculty of Science, Sabratha University, Sabratha, Libya
Corresponding email. ali.madour@sabu.edu.ly

Abstract
Sickle cell disease (SCD) is a global health challenge and has been recognized by the World Health Organization as a public health priority due to limited diagnostic and treatment services. In Libya, the prevalence of SCD varies widely across regions, yet little is known about available resources and management strategies, and treatment services. This study was conducted to document the existing facilities and assess current practices for SCD management at the National Institute of Oncology, Sabratha, which hosts the only dedicated SCD clinic in the region. A cross-sectional questionnaire survey was structured questionnaires completed by lab workers and physicians responsible for managing SCD patients at the SCD clinic at the National Institute of Oncology, Sabratha. The clinic registered only 10 patients, indicating a low reported incidence of SCD in the region. Patients had access to microbiology and chemistry laboratories, as well as CT and MRI imaging. However, several essential diagnostic and monitoring tools were absent. The clinic did not possess facilities for β-globin gene analysis, automated cell counters, haemoglobin electrophoresis, high-performance liquid chromatography (HPLC), or transcranial Doppler ultrasound. In addition, there were no new-born screening programs or photoelectric concentration equipment available. The findings highlight both a low prevalence of SCD in the region and significant gaps in diagnostic and laboratory capacity. Strengthening infrastructure and expanding diagnostic services are critical to improving early detection, monitoring, and comprehensive management of SCD in the region.
Keywords. *Sickle Cell Disease, Current Practices, Management, Libya*

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Introduction

Sickle cell disease (SCD) is one of the most common hereditary disorders worldwide, causing substantial morbidity and mortality [1]. Of the 330,000 infants born annually with major hemoglobinopathies, about 275,000 are affected by SCD, making it the most prevalent global hemoglobinopathy [2,3,4]. The sickle haemoglobin (HbS) gene occurs at variable frequencies across the Middle East and North Africa. Although advances in screening and treatment have reduced childhood mortality, life expectancy, and quality of life for people with SCD remain significantly lower than for unaffected populations [5,6].

Early diagnosis through haemoglobin electrophoresis, newborn screening with high-performance liquid chromatography or isoelectric focusing, and prenatal genetic testing improves outcomes [7,8,9]. Effective management strategies include hydroxyurea therapy, vaccination, prophylactic antibiotics, folic acid supplementation, and structured pain control, all of which reduce complications and improve survival [10.11,12]. Without comprehensive management, SCD can lead to multi-organ complications, including chronic anaemia, recurrent pain crises, musculoskeletal dysfunction, stroke, acute chest syndrome, and recurrent infections.

The World Health Organization (WHO) has recommended comprehensive care policies including antibiotic prophylaxis, malaria prevention, vaccination, early complication detection, and continuous medical follow-up. However, implementation remains a challenge in many countries, including Libya [13].

In Libya, structured programs and widespread initiatives for SCD remain limited, and adherence to standardized care practices appears inconsistent. To address this gap, the present study aimed to document the existing facilities and assess current diagnostic approaches and management practices for SCD at the National Institute of Oncology in Sabratha, which hosts the only dedicated SCD clinic in the region.

Materials and Methods

Study design

A cross-sectional study was conducted at the National Institute of Oncology in Sabratha, Libya, from February to May 2024. This centre serves as the only specialized center providing dedicated clinics for sickle cell disease (SCD) in the region. Although multiple public and private healthcare facilities exist in Sabratha and surrounding villages, SCD management is centralized at this institute.

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Study population
Patients diagnosed with sickle cell anemia who regularly receive blood transfusions at the National Institute of Oncology were included. Subjects were recruited from Sabratha city and neighboring villages.

Data collection from medical records
Clinical data, including presenting symptoms, signs, and management history, were extracted from patients' medical files and reports. This process was carried out by a physician affiliated with the clinic to ensure accuracy and completeness.

Questionnaire survey
Additional data were obtained through a structured questionnaire administered to lab workers and specialist physicians working exclusively in the dedicated SCD clinics. The questionnaire aimed to assess available facilities, diagnostic laboratory tests, instrumentation, and therapeutic options for SCD patients within the institute. Physicians and lab workers were encouraged to complete the questionnaire independently.

Data handling and confidentiality
Responses from the questionnaire and patient files were collected and compiled by the research team. To ensure confidentiality and anonymity, no identifying information, such as names or signatures, was recorded.

Results
Burden of disease in Sabratha city and its environs
In this study, data were retrieved from patients' paper-based files maintained at the sickle cell disease (SCD) clinic of the National Oncology Institute, Sabratha, which has one SCD clinic, and this clinic is mixed, i.e., with both adult and paediatric patients. The records included information on clinical symptoms and signs of sickle cell anemia as well as medical reports prepared by attending lab workers and physicians. Although the clinic maintained a medical records department, the documentation system was not computerized, and many files were incomplete, limiting the comprehensiveness of data collection.
At the time of assessment, only 10 patients were registered and actively followed in the SCD clinic. The age distribution ranged from 14 to 50 years, with the majority being female patients (n=7, 70%), while male patients accounted for 30% (n=3) (Table 1).

Table 1. Demographic and laboratory data of the study group.

Sex	Screening	Drug used	Ferritin test	MCH (pg) per cell	MCV (fL)	HB (g/dL)	WBC cells x 10^9/L	RBC million cells/mcL	Associated disease	Genotype	Age (years)	Origin
Female	CBC/ ESR	No record	No record	32.1	84.8	6.9	14.6	2.1	No record	No record	17	Almutrad
Female	CBC/ ESR	No record	No record	33.5	97.42	7.5	25.9	2.25	No record	No record	31	Sabratha
Female	CBC/ ESR	No record	No record	25.4	72.4	10.4	4.5	4.1	No record	No record	35	Zuwara
Female	CBC/ ESR	No record	No record	32.2	91.7	9.4	14.3	2.7	No record	No record	16	Zuwara
Male	CBC/ ESR	No record	No record	30.2	89.4	8.2	17.1	2.44	No record	No record	30	Jumayl
Female	CBC/ ESR	No record	No record	31	88.7	9.5	11.1	4.7	No record	No record	33	Sabratha
Male	CBC	Aspirin 75mg	No record	29.8	91.3	8.7	19.62	2.93	No record	No record	17	Ajaylat
Male	CBC	No record	No record	31.9	91.5	8	17.3	2.5	No record	No record	21	Zawiya
Female	CBC	No record	No record	30.2	91.3	7	9.5	2.3	No record	No record	50	Zawiya
Female	CBC	No record	No record	30.8	87.1	7.4	14.9	2.3	No record	No record	14	Sabratha

Characteristics and practices in the SCD clinic
The institutional medical records department existed, but there was no dedicated database of SCD patients, either electronic or paper-based, to facilitate longitudinal tracking and follow-up (Table 2).

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Table 2. Characteristics and practices in the sickle cell disease (SCD) clinic

Characteristics and practices in the sickle cell disease (SCD) clinic	
Number of patients currently being followed	10
Is there an institutional medical records department?	Yes
Is there a database of SCD patients, and if so, what type?	No

Management practices in the SCD clinic at the National Oncology Institute–Sabratha

A structured questionnaire administered to specialist physicians and lab workers revealed important gaps in diagnostic and monitoring facilities. The clinic did not have access to automated hematology analyzers, hemoglobin electrophoresis, high-performance liquid chromatography (HPLC), transcranial Doppler ultrasound, newborn screening programs, or photoelectro-concentration equipment. Basic microbiology and clinical chemistry services were available to all patients; however, no molecular laboratory capacity was present for β-globin gene analysis or advanced genetic profiling. Imaging services were relatively well established, with patients having access to both computed tomography (CT) and magnetic resonance imaging (MRI) facilities (Table 3).

Table 3. Facilities available in the sickle cell disease clinic

Facilities available in the sickle cell disease clinic	
Electronic cell counter	No
Hb electrophoresis	No
high-performance liquid chromatography	No
New-born screening	No
Isoelectric focusing	No
Microbiology laboratory	Yes
Chemistry laboratory	Yes
Molecular biology laboratory	No
CT	Yes
MRI	Yes
Transcranial Doppler ultrasound	No

With regard to treatment practices, the clinic routinely prescribed folic acid supplementation and hydroxyurea as part of standard care. Nonetheless, prophylactic penicillin, pneumococcal vaccination, and other preventive/supportive therapies were not implemented as part of routine management (Table 4).

Table 4. Treatment and drugs used in the sickle cell disease clinic

Is there regular use of the following	
Folic acid	Yes
Penicillin prophylaxis	No
Vaccination against Streptococcus pneumoniae and Hib (PCV, Hib)	Yes
Hydroxyurea	Yes
Is there use of other medications, including herbal preparations?	No

These findings highlight significant deficiencies in both diagnostic infrastructure and preventive care, which may adversely impact the quality of care and long-term outcomes for SCD patients in Sabratha and surrounding areas.

Discussion

Burden of Sickle Cell Disease in Sabratha and Surrounding Areas

This study was conducted in Sabratha city and its surrounding areas between February and May 2024. Although several public and private health facilities operate in the region, the National Institute of Oncology remains the only center with a dedicated sickle cell disease (SCD) clinic. Despite the clinic's wide catchment area, only 10 patients were registered during the study period. This relatively small number may indicate a lower burden of SCD in this part of Libya. These findings are consistent with previous studies. El-Hazmi et al [14] reported a low prevalence of abnormal hemoglobins among the indigenous Libyan population, while Marwan [15] documented a prevalence of 1.6% for HbAS and no cases of HbSS. Similarly, studies in Benghazi and Wadi Elshati reported carrier rates of 4.2% and 4.15%, respectively

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[16,17]. In contrast, markedly higher frequencies have been documented in southern Libya. Elasbali [18] found HbAS in 53.34% of the population and HbSS in nearly 10% in the Marzouk region, with the high rate of consanguinity (72%) identified as a key contributing factor. Jornaz [19] also reported a prevalence of 12.5% among the Taourga population. These higher rates are partly explained by the distinctive genetic background of these communities, which includes admixture between Arab and sub-Saharan African ancestry, populations where SCD is historically more prevalent [19].

Management Practices in the SCD Clinic at the National Oncology Institute, Sabratha

Evaluation of diagnostic and management practices at the National Oncology Institute revealed important gaps. Questionnaire data from physicians and laboratory staff showed that while patients had access to CT and MRI imaging, and basic microbiology and chemistry laboratories, the clinic lacked essential diagnostic infrastructure. Facilities for molecular testing of the β-globin gene, electronic cell counters, hemoglobin electrophoresis, high-performance liquid chromatography (HPLC), newborn screening, and photoelectric concentration analysis were unavailable. Similar deficiencies have been reported in other African countries [20,21,22,23] in contrast to high-income settings where HPLC, capillary electrophoresis, and isoelectric focusing are routinely used for SCD screening and confirmation [20].

As the sole specialized center in the region, the clinic should be equipped with at least hemoglobin electrophoresis and HPLC for confirmatory diagnosis. Furthermore, it must have the capacity to manage common complications, including severe anemia, vaso-occlusive crises, infections, acute chest syndrome, gallstones, leg ulcers, and stroke. The absence of critical equipment, such as transcranial Doppler (TCD) for stroke risk screening, erythrocytapheresis machines, and facilities for quantifying hemoglobin S (HbS) and hemoglobin F (HbF), represents a serious gap in care. Considering that ischemic stroke is one of the most devastating yet preventable complications of SCD, the implementation of TCD is a priority.

In terms of treatment, all patients in this clinic received hydroxyurea, a finding that contrasts with studies from other African contexts, such as Kambale-Kombi [20], where only 5.1% of patients were prescribed hydroxyurea. Limited caregiver knowledge has been cited as a reason for underuse elsewhere. The universal administration of hydroxyurea in Sabratha is therefore a positive practice aligned with evidence demonstrating its safety and efficacy in reducing SCD morbidity and mortality [24-26].

Folic acid supplementation was also routinely prescribed for all patients. This practice aligns with findings from Kinshasa, where 98% of patients received folic acid [27] but differs from other regions of the Democratic Republic of Congo, where less than half of patients were prescribed supplementation [20]. Since SCD patients are at increased risk of folate deficiency due to chronic hemolysis, folic acid is critical for replenishing stores and mitigating anemia [20,28,29].

Infection prevention is another cornerstone of SCD management. *Streptococcus pneumoniae* and *Haemophilus influenzae* type b (Hib) remain leading causes of morbidity and mortality, particularly in children. Penicillin prophylaxis and immunization are widely endorsed strategies [21,22,30], and the CDC recommends pneumococcal vaccination for all children with SCD, including those over 5 years who may not have been fully immunized [31]. In the present study, all patients had received Hib and pneumococcal vaccines through Libya's national immunization program, reflecting strong vaccine coverage. However, like findings from other African studies [20,32], penicillin prophylaxis was not consistently administered, leaving patients vulnerable to serious infections.

Conclusion and Public Health Implications

The findings of this study highlight both strengths and shortcomings in SCD management in the National Institute of Oncology. While universal provision of hydroxyurea and folic acid represents best practice, the absence of confirmatory diagnostics, limited laboratory capacity, lack of TCD screening, and inconsistent penicillin prophylaxis indicate major deficiencies. Addressing these gaps requires investment in infrastructure, training of healthcare personnel, and establishment of standardized national protocols for SCD care. Policymakers should consider integrating SCD services into broader public health programs and prioritizing the allocation of resources to specialized centers such as the National Institute of Oncology. Enhancing diagnostic facilities, ensuring consistent access to essential medications, and expanding preventive services will be crucial steps toward improving patient outcomes and reducing the long-term health and socioeconomic burden of SCD in Libya.

Limitations

This study had several limitations. First, the number of patients registered at the Sabratha SCD clinic was small, which may not accurately reflect the true prevalence of the disease in the wider community. Second, the absence of a centralized, computerized medical record system restricted access to complete clinical and laboratory data, thereby limiting the depth of analysis. Third, advanced diagnostic facilities, such as hemoglobin electrophoresis, HPLC, and transcranial Doppler screening, were not routinely

available, which constrained comprehensive disease confirmation and risk assessment, reflecting broader systemic gaps in infrastructure and standardization of care.

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