

## Original Article

# Sickle cell disease in Jharkhand: A registry-based evaluation of disease burden and healthcare needs

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**Background and objectives:** Sickle cell disease poses a significant healthcare burden across several regions and states in India. We present findings from a sickle cell anaemia registry in the State of Jharkhand, a tribal predominant state situated in Eastern India, to provide an insight into the clinico-epidemiological profile and need-based management of sickle cell anaemia.

**Methods:** Sickle cell disease Registry at Rajendra Institute of Medical Sciences (RIMS), Ranchi, Jharkhand was started in the year 2022 and it has 334 sickle cell disease patients recruited over two and a half years. This clinical research provides systematically captured comprehensive data of sickle cell anaemia patients with *HbSS* genotype, including demographics, clinical presentation, laboratory findings, treatment modalities, complications, and their outcomes.

**Results:** Clinical manifestations varied from mild to severe, with the most common presentation being vaso-occlusive crises (n=257, 94.5%). A significant proportion of patients required blood transfusion n=260, (95.6%). Hydroxyurea the mainstay of treatment, was taken regularly by 136, (50%) of patients, whereas n=68, 25% were irregularly taking hydroxyurea medication and n= 68, 25% never took it. Regular intake of hydroxyurea therapy was significantly associated with reduction in pain crises and a decreased need for blood transfusion.

**Interpretation and conclusions:** Establishment of hydroxyurea monitoring units, monitoring of blood transfusion through appropriate investigations, increased utilisation of iron chelation therapy, and identification of patients with increased stroke risk can lead to improved patient care, escalated awareness and reduced rate of hospitalisation in sickle cell disease.

**Keywords** Hemoglobinopathies; Hydroxyurea therapy; Jharkhand; Registry; Sickle cell disease; Vaso-occlusive crisis

Sickle cell disease (SCD) is a hereditary hemoglobinopathy characterised by the presence of abnormal haemoglobin S, leading to chronic haemolytic anaemia, vaso-occlusive crises, and multiorgan damage.<sup>1</sup> It is a significant public health concern, particularly in regions with high prevalence, such as sub-Saharan Africa, the Middle East, and parts of India.<sup>2</sup> Despite advances in management, SCD remains associated with high morbidity and mortality, especially in low-resource settings.<sup>3</sup>

India, with a projected population of 1.45 billion in 2024, has a tribal population comprising 8.6% of its total distribution, across various State.<sup>4</sup> Jharkhand has

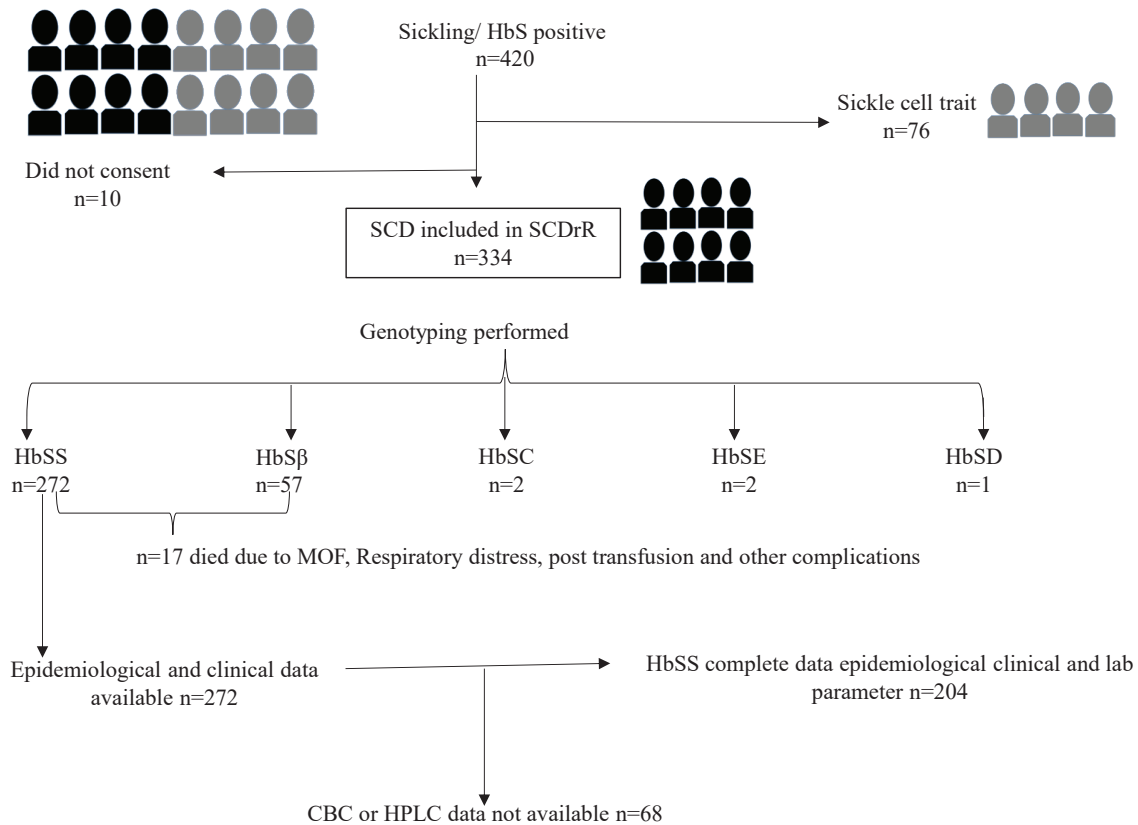
26% of its population belonging to 32 different tribal communities.<sup>5</sup> Although a high prevalence of sickle cell disease has been reported in the State, there is lack of studies providing accurate epidemiological data.<sup>6,7</sup> The Indian National Sickle Cell Elimination Program aims to address the significant health challenges faced by SCD patients, particularly among the tribal populations and to eliminate the disease as a public health problem by the year 2047.

Clinical heterogeneity exists among different ethnicities and geographical locations across the nation.<sup>1</sup> While studies representing sickle cell disease populations from various States are available, there is

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**Figure.** This figure presents the flow chart showing recruitment of study participants as well as availability of epidemiological and clinical data in SCDrRR. SCD, sickle cell disease; HbSC, haemoglobin SC disease; HPLC, high-performance liquid chromatography; CBC, complete blood count.

a paucity of such data from Jharkhand.<sup>7</sup> Establishing the registry is crucial for understanding the disease prevalence and progression, enabling better monitoring and treatment strategies. This paper emphasises the need to scale up the sickle cell disease registry across Jharkhand to aid in programme planning, disease prevention, and management.

## Methods

**Study design:** This was a Registry-based prospective observational study. The Sickle Cell Disease Registry at Rajendra Institute of Medical Sciences (RIMS), Ranchi (SCDrRR), Jharkhand, India, provides systematically captured comprehensive patient data, including demographics, clinical presentation, laboratory findings, treatment modalities, complications, and outcomes. SCDrRR was established in the department of Genetics and Genomics in collaboration with the departments of Paediatrics, Medicine, and Obstetrics and Gynaecology, RIMS, Ranchi, a tertiary care institute in Eastern India. Informed consent/assent was obtained from patients or, when applicable, from their parents or guardians. Ethical approval was obtained

by the Institutional Ethics Committee, RIMS, Ranchi. Confidentiality of study participants and data security were strictly maintained throughout the study.

**Study objectives:** The primary objective was to study the clinical profile of sickle cell disease patients having *HbSS* genotype referred to our hospital for disease management over a two and a half year period. The secondary objectives were to determine the predictors of vaso-occlusive crisis in *HbSS* and to study the epidemiological profile of the patients in the hospital-based sickle cell disease registry.

**Study setting:** There were 420 sickling positive patients out of which 76 were sickle cell trait. This study presents demographic data for 334 patients registered in SCDrRR during July 2022 till December 2024. Clinical data analysis was conducted for 272 patients with *HbSS* genotype. Haematological and HPLC data were available only for 204 patients among homozygous genotypes. **Figure** presents the flow chart depicting inclusion of study participants in SCDrRR.

**Participant selection:** Inclusion criteria were genotypically confirmed cases of *HbSS*, age group 2-65

yr and no history of blood transfusion in past 6 wk. The exclusion criteria were unwillingness to participate in the study, pregnant women, patients diagnosed with arthritis, or any other chronic conditions associated with joint pain, chest pain or abdominal pain and patients with severe acute or chronic illness other than sickle cell disease.

*Study variables:* SCD patients were classified into five molecular subgroups (*HbSS*, *HbSβ*, *HbSE*, *HbSC* and *HbSD*) depending upon the genotypic data. An episode of vaso-occlusive crisis was defined as the occurrence of pain in the extremities, back, abdomen, chest, or head that lasted at least two hours, led to a clinic visit, and could not be explained except by sickle cell disease.<sup>8</sup> Anaemia was categorised as severe, moderate or mild when haemoglobin concentrations were <7 g/dL, 7-10 g/dL, or more than 10 g/dL, respectively.<sup>9</sup>

*Data collection and data management:* A standardised data collection form was developed to ensure consistency and completeness. Trained researchers systematically recorded patient data in an electronic database using the REDCap tool. The data collection took place in various wards of RIMS, a premier tertiary care institute in Eastern India, where patients sought disease management.

As part of SCDrRR study protocol, 3–5 mL of blood was collected from each recruited patient in EDTA vacutainers. DNA was extracted using a modified salting-out method to obtain high-quality genetic material. The purity and concentration of the extracted DNA were assessed using Multiskansky high from Thermo Fisher Scientific. Genotypic characterisation of all patients was performed using capillary sequencing on the SeqStudio Flex Genetic Analyzer, Applied Biosystems (Thermo Fisher Scientific, MA, USA), allowing for precise genetic profiling. To minimise selection bias, all consecutive admitted or OPD patients with sickle cell anaemia were included in the study. To minimise recall bias, medical records were used to verify the data on total number of transfusions, total number of vaso-occlusive crises, and use of medications. Same confirmatory method and platform of molecular testing was used for all the patients minimising measurement bias. All the samples were de-identified after DNA extraction.

To maintain data integrity, regular audits were conducted to verify completeness and accuracy. Additionally, periodic data analysis was performed to generate reports on disease trends, healthcare utilisation, and patient outcomes. These efforts contributed to a

comprehensive understanding of the disease burden and helped improve patient management strategies.

*Follow up:* Patients in SCDrRR were followed up at 6 months interval till the end of one year. Among 272 *HbSS* patients, 175 patients completed a followed up of one year by December 2024 whereas 214 patients completed follow up of 6 months only. 58 patients were lost to follow up due to inability to contact on the two mobile numbers that were given by the patients or their relatives. The data was used to generate reports on disease trend and patient outcomes.

*Statistical analysis:* Descriptive statistics were used for the representing the baseline characteristics and demographics data. Continuous variables are summarised in mean and standard deviation or median or interquartile range. The categorical variables are presented as count and percentages. We conducted linear regression analysis to determine the predictors for the vaso-occlusive crises with key predictors like total leukocyte count, age, total number of transfusions, and regular use of hydroxyurea. The analysis included univariate, stepwise regression analysis with removal probability (0.20) and multivariable linear regression analysis. Model fit was examined by R-squared. Statistical significance was defined at a two-sided alpha of 0.05. All the statistical analyses were conducted using the STATA software version 18 (Boston College, USA).

## Results

A total of 334 patients either homozygotes or compound heterozygotes for SCD were entered into the registry. The most common genotype was *HbSS*, observed in 272 cases (81.2%). The epidemiological characteristics of the patients enrolled in the Sickle Cell Disease Registry at RIMS, Ranchi (SCDrRR) are detailed in **Table I**.

Clinical characteristics of the SCDrRR patients are detailed in **Table II**. Hematological and HPLC parameters in patients with *HbSS* phenotype are shown in **Table III**.

Vaso-occlusive crisis was the most common clinical presentation among *HbSS* patients for hospital admission. The mean number of vaso-occlusive crises in males was 4.41 (95% CI: 3.92–4.89), whereas in females, it was 4.06 (95% CI: 3.41–4.71). The difference between the two groups was statistically insignificant ( $P=0.395$ ). In the present study, crisis episodes were significantly lower in patients taking hydroxyurea

**Table I. Epidemiological characteristics of patients in SCDrRR**

Characteristics (n=334)	Frequency (%) or Mean (CI)
Age (yr)	
0 - <5	16 (4.8)
5 - <10	70 (20.9)
10 - <20	155 (46.4)
20 - <30	68 (20.4)
30 - <40	19 (1.8)
40 - <60	07 (1.7)
Gender	
Male	213 (63.8)
Female	121 (36.2)
Genotype of the SCA patients	
<i>HbSS</i>	272 (81.2)
<i>HbSβ</i>	57 (17.0)
<i>HbSE</i>	02 (0.6)
<i>HbSC</i>	02 (0.6)
<i>HbSD</i> (Punjab)	01 (0.3)
Caste-based category of the patients in the registry	
Scheduled tribe (ST)	154 (46.1)
Scheduled caste (SC)	44 (13.2)
Other backward class (OBC)	73 (21.9)
General	63 (18.8)

CI, confidence interval; SCA, sickle cell anaemia

regularly as compared to the patients who were either irregular or not on hydroxyurea therapy (mean 2.9; CI: 2.6,3.2 *versus* mean 5.7; CI: 5.1,6.3) ( $P<0.001$ ). The patients who had ever taken hydroxyurea (regular and irregular) did not have lesser number of painful crises as compared to the patients who did not take at all. However, we observed a significant negative correlation ( $P<0.001$ ) between regular intake of HU and number of vaso-occlusive crises in the patients.

Healthcare utilisation in terms of blood transfusion was high among *HbSS* genotype. Average number of RBC transfusion was 16.7 (95% CI: 13.8, 19.6). The mean time interval between the transfusions was 10.5 (95% CI: 8.6,12.4) months. Post-transfusion adverse reactions occurred in 47 (18.1%) patients. Serum iron and ferritin studies were done only in 13 (4.8%) and 25 (9.19%) patients respectively. Mean iron level was 69.3 (CI 32.9, 105.7) ug/dL and mean ferritin level was 2063.7 (CI 929.8, 3197.5) ng/mL.

Death was reported in 14 patients (5.1%) and the mean age at death was (22.5±12.2) years for *HbSS* patients. The causes of death included respiratory distress (n=9, 64.3%), multiple organ failure (n=2, 14.3%), post-transfusion complications (n=2, 14.3%)

**Table II. Clinical features and Parameters of therapeutic intervention in patients with *HbSS* genotype**

Variables (n=272)	Number (%)
Vaso-occlusive crisis	257 (94.5)
0-2	84 (32.7)
3-4	80 (31.2)
≥ 5	93 (36.0)
Severity anaemia	
Severe	138 (50.7)
Moderate	123 (45.2)
Mild	11 (4.0)
Acute chest syndrome	116 (42.6)
Stroke	11 (4.0)
Priapism	4 (1.5)
Splenic sequestration	40 (14.7)
Splenomegaly	55 (20.2)
Hepatobiliary complications	68 (25)
#Transaminitis	45 (16.5)
Cirrhosis	15 (5.5)
#Cholelithiasis	08 (2.9)
Diastolic heart dysfunction	18 (6.6)
Acute severe headache	45 (16.5)
Joint pain	213 (78.3)
Chest pain	172 (63.2)
Pulmonary hypertension	10 (3.7)
Recurrent abdominal pain	40 (14.7)
Recurrent loss of consciousness	137 (50.4)
Acute cerebrovascular symptom	78 (28.7)
Avascular necrosis	9 (3.3)
Seizure	15 (5.5)
Leg ulcer	5 (1.8)
Transient loss of vision	3 (1.1)
Transient ischemic attack	4 (1.5)
Hydroxyurea (HU) medication status	
Regularly taking HU	136 (50)
Irregularly taking HU	68 (25)
Not on HU	68 (25)
Ever received blood transfusion	260 (95.6)
Post transfusion adverse reaction	47 (18.1)
Mortality	14 (5.1)

#One patient had both transaminitis and cirrhosis, another patient had transaminitis and cholelithiasis both and among the patients with transaminitis, 4.4% had SGPT > 3 times URL

and stroke (n=1, 7.1%). Penicillin prophylaxis was uncommon; only one (6.25%) of younger children (age <5 yr) received antibiotic prophylaxis. Pneumococcal vaccination was done in five (1.84%) individuals.

**Table III. Haematological and HPLC parameters in patients with *HbSS* genotype**

Parameters (n=204)	Mean	Standard error	95% CI
Haemoglobin (g/dL)	7.9	0.141	7.65- 8.21
Haematocrit (%)	25.1	0.430	24.18- 25.87
Mean corpuscular volume (fL)	83.5	1.08	81.34- 85.59
Mean corpuscular Hb concentration (g/dL)	31.5	0.27	30.94-32.01
Red cell distribution width (%)	19.5	0.567	18.37-20.61
Total leucocyte count (X10 <sup>3</sup> /uL)	11.4	0.492	10.45-12.39
Neutrophil count (%)	57.6 %	1.202	55.21-59.96
Platelet count (X10 <sup>3</sup> /uL)	192.9	7.959	177.24-208.64
<b>HPLC parameters (%)</b>			
HbA0	6.45	0.73	5.02-7.88
HbA2	2.80	0.194	2.42-3.18
HbS	70.34	0.734	68.89- 71.79
HbF	18.33	0.541	17.27-19.39

**Regression analysis:** On univariate analysis, High total leukocyte count was statistically significantly associated with the increase in the vaso-occlusive crises per year ( $P=0.035$ ). Regularly using hydroxyurea was found to be statistically significantly associated with the with lower painful crisis episodes ( $P<0.001$ ), indicating protective effects. Total number of transfusions was associated with higher vaso-occlusive crises in patients with sickle cell disease ( $P<0.001$ ). Other variables like gender, haematocrit, MCV, haemoglobin, platelet count, neutrophil, history of stroke were not significantly associated with number of crises per year. Multivariate linear regression was performed to assess whether TLC, age, number of transfusions, and regular use of hydroxyurea predict the number of vaso-occlusive crises in patients with sickle cell disease ( $n=272$ ). The overall model was statistically significant ( $P<0.001$ ), indicating approximately 21.7% of variance in the number of painful crisis per year. Regular use of hydroxyurea was significantly associated with a reduction in the frequency of vaso-occlusive crises ( $P<0.001$ ). Total leukocyte count was also found to be an independent predictor for increase in the number of crises per year ( $P=0.019$ ). Further, we categorised the patients based on age ( $< 5$ ,  $>5-20$ , and  $>20$  yr), Total leukocyte count ( $\leq 10,000/\text{cmm}$  and  $>10,000/\text{cmm}$ ) and number of transfusions ( $\leq 12$  and  $>12$ ). On multivariate analysis for prediction of vaso-occlusive crises using the different categories of age, total leukocyte count, and total number of transfusions, no difference in the effects was observed within these categories. A univariable regression analysis was conducted to determine the association between various clinical and haematological parameters and

the occurrence of acute cerebrovascular symptoms in patients with sickle cell disease. Neutrophil percentage was significantly positively associated with acute cerebrovascular symptoms ( $\beta=0.003$ ,  $P=0.003$ ).

### Discussion

The clinical characteristics of 272 sickle cell disease patients in our registry revealed severe phenotypic presentation of sickle cell disease in Jharkhand. Vascular crisis was the most common complication. Approximately two third patients presented with severe anaemia and several patients experienced stroke related symptoms. In the comprehensive care model of Western India, 35.4% patients had  $\geq 3$  episodes of painful crises as compared to 67.3% in our study.<sup>10</sup> In a retrospective analysis of 250 sickle cell disease patients in North East of India, vascular crisis was present only in 48.4% patients.<sup>11</sup> In another retrospective study of 316 sickle cell disease patients from Central India, 52.5% had painful crises requiring hospitalisation.<sup>12</sup> In another prospective hospital-based study from Central India that followed 325 children, vaso-occlusive crises was present in 65.3%.<sup>13</sup> Our registry patients had a higher number of vaso-occlusive crises as compared to Indian Sickle Cell Disease Registry (ISCDR), Central India and North East of India studies as well as multicentric Oman study where three or more episodes of painful crises per year occurred in only 36.6%.<sup>6,11-14</sup>

In our study, crisis episodes were significantly lower in patients taking hydroxyurea therapy regularly. This was consistent with the findings in comprehensive care model of SCD among Rural Western population of India where with hydroxyurea therapy, vaso-occlusive

crises episodes ( $\geq 3$  per yr) decreased from 35.4% to 9.8% ( $P < 0.001$ ).<sup>10</sup> These findings highlight the need for hydroxyurea monitoring units in sickle cell anaemia care centres. Our cohort also had more severe anaemia (67.3%) requiring frequent blood transfusions as compared to ISCDR, where severe and moderate anaemia was present in 30.56% and 66.05% patients, respectively<sup>6</sup>. Blood transfusion history revealed that 95.6% of patients had received at least one transfusion in lifetime, the number being high as compared to studies from north, east, central India, and rural western India where blood transfusion occurred in 72.4%, 76.6%, and 26.2%, respectively.<sup>10-12</sup> Use of transfusion therapy without clear indications resulted in adverse clinical outcomes and increased economic burden.<sup>15</sup> Despite a high number of RBC transfusion and a high serum ferritin levels in *HbSS* group in this study, only three patients (1.1%) were on iron chelation therapy as compared to 22.4% in North Eastern SCA study.<sup>11</sup> In a randomised double-blind trial, 3 months treatment with 150 mg/kg/day deferoxamine caused a 33% to 60% reduction in serum ferritin and demonstrable improvement in hepatic function in all patients. No toxicity was encountered in these patients.<sup>16</sup> Further, in a recent study, administration of iron chelation drugs with hydroxyurea improved clinical symptoms and prevented hydroxyurea induced DNA damage.<sup>17</sup> The findings suggest that iron chelation may be beneficial in SCD despite differences in the biology of iron overload between SCD and thalassaemia. We emphasise that iron-related organ damage in SCD is under recognised, partly because the damage is often attributed to SCD itself.<sup>18</sup> SCD related organ damage (hepatic involvement and cardiac involvement) was present in 28.8% patients in this study that further highlights the need for studies on iron status and iron chelation especially in the patients with multiple transfusions.

Overt stroke, transient ischemic attack, acute severe headache, and seizure were present in 28.7% of patients, highlighting the fact that most SCD patients experience cerebrovascular symptoms.<sup>19</sup> This underscores the importance of transcranial doppler and magnetic resonance imaging studies in detecting cerebral complications. Identification of this subgroup of SCD and strategic management with erythrocyte transfusion and iron chelation therapy may help in decreasing stroke related morbidity and mortality. Additionally, several genetic factors contribute to stroke risk in SCD and may help to identify therapeutic targets.<sup>19,20</sup> Mortality of 5.1% was present in our patients over a period of one year follow up as compared to

1.8% in the comprehensive care model of Gujrat.<sup>10</sup> This necessitates better management strategies to improve survival outcomes in SCD.

Strength of this study includes prospective nature of the study, robust clinical data and enrolment of patients coming from different districts of the tribal predominant state, Jharkhand during the study period. Further, we performed genotyping of all the patients included in the registry to confirm the type of hemoglobinopathy. Limitations of the study include a smaller number of participants, inclusion of single centre and unavailability of CBC and HPLC reports in few of the documented cases of SCD. Despite the lack of HPLC reports in some of the patients, no selection bias was introduced as we used genotyping for disease confirmation.

Implications of the study include implementation of hydroxyurea monitoring units in sickle cell anaemia care centres for long-term adherence to hydroxyurea therapy thereby reducing the need for blood transfusion. Additionally, for patients requiring high number of blood transfusions, practices of iron profile studies should be implied. In cases of high ferritin levels or in high iron storage conditions, provision and availability of iron chelation therapy should be ensured by the policy makers. Further, availability of transcranial doppler studies should be ensured in sickle cell disease care centres for identification of increased stroke risk and strategic planning for long term blood transfusion. Integrating the therapies into sickle cell comprehensive care units will improve patient outcomes and reduce overall disease burden.

**Author contributions:** AP: Conceived and coordinated, statistical analysis, intellectual content, manuscript writing; AK: Data acquisition and analysis, manuscript writing; KK: Data acquisition and analysis; PKC: Provided samples, manuscript writing, intellectual content; SS: Data interpretation, intellectual content, manuscript writing; GC: Intellectual content, manuscript writing; SK: Provided samples; AVK: Manuscript writing, intellectual content; AK: Statistical analysis; RTG: Provided samples, intellectual content, manuscript writing. All authors have read and approve the final printed version of the manuscript.

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### शोध-संदेश

यह अध्ययन भारत के पूर्वी भाग में स्थित, जनजातीय बहुल राज्य झारखण्ड में सिकल सेल एनीमिया की स्थिति पर आधारित है और राज्य-स्तरीय रजिस्ट्री से प्राप्त ठोस निष्कर्ष प्रस्तुत करता है। शोध का उद्देश्य सिकल सेल एनीमिया से ग्रसित रोगियों की क्लिनिको-एपिडेमियोलॉजिकल प्रोफाइल को समझना तथा आवश्यकता-आधारित प्रबंधन की दिशा को स्पष्ट करना था। अध्ययन से यह निष्कर्ष निकला कि सिकल सेल एनीमिया से लड़ने के लिए हाइड्रोक्सीयूरिया मॉनिटरिंग इकाइयों की स्थापना, उचित जांचों के माध्यम से रक्त आधान की निगरानी, आयरन चेलेशन (iron chelation) थेरेपी के उपयोग में वृद्धि, तथा स्ट्रोक के उच्च जोखिम वाले रोगियों की पहचान जैसे उपाय, कारगर सिद्ध हो सकते हैं। इन उपायों से रोगियों की देखभाल में सुधार होता है। जागरूकता में वृद्धि और अस्पताल में भर्ती होने की दर में कमी लाई जा सकती है।

**Conflicts of Interest:** None.

**Use of Artificial Intelligence (AI)-Assisted Technology for manuscript preparation:** The authors confirm that there was no use of AI-assisted technology for assisting in the writing of the manuscript and no images were manipulated using AI.

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