A Comprehensive Study On Sickle Cell Disease (SCD)

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ABSTRACT

Sickle cell disease (SCD) is one of the most prevalent monogenic disorders worldwide, caused by a point mutation in the β-globin gene that leads to the production of abnormal hemoglobin S. Under deoxygenated conditions, hemoglobin S polymerizes, distorting red blood cells into a sickle shape and resulting in hemolysis, vaso-occlusion, and multi-organ complications. The burden of SCD is especially significant in sub-Saharan Africa, the Middle East, and India, where it disproportionately affects tribal and marginalized populations. Recent epidemiological data highlight that India accounts for a substantial share of global cases, with high prevalence in central and eastern states. Despite advances in screening and newborn diagnostic programs, delayed diagnosis and inadequate access to comprehensive care continue to contribute to high morbidity and mortality.

In this study Special emphasis is given to current knowledge on the sickel cell morphology, do's & dont's to control SCD, sensitive areas, Govt. initiatives, data analysis at surrounding area for district Balaghat (MP), survey methodology for SCD sample collection, pathophysiology, current situation of SCD in India, In conclusion, while significant progress has been made in understanding and managing SCD, bridging the gaps in early detection, affordable treatment, and equitable health access remains critical. Future prospects lie in integrating advanced therapeutics with community-based prevention programs to move toward disease elimination. A review on SCD is not only academically valuable but also socially relevant, as it integrates scientific knowledge with public health needs, helping to move toward better management and eventual elimination of the disease.

KEYWORDS: Sickle cell anemia (SCA), Sensitive Areas, Red blood cells, National Sickle Cell Anaemia Elimination Mission, Sample collection

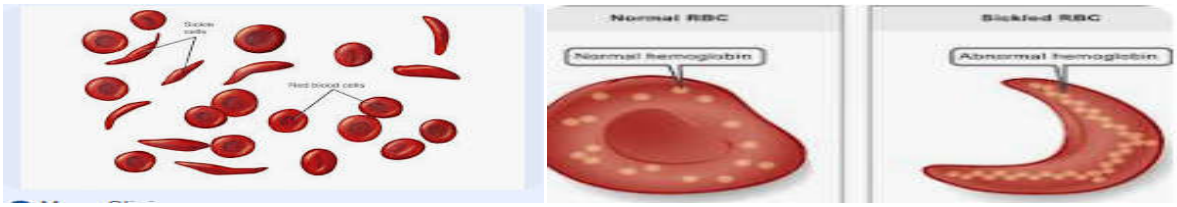
INTRODUCTION TO SICKLE CELL ANEMIA

Sickle cell anemia (SCA) is a genetic blood disorder caused by an inherited mutation in the gene responsible for producing hemoglobin, the protein in red blood cells that carries oxygen throughout the body. In this condition, the normal round and flexible red blood cells are replaced with abnormally shaped, rigid, crescent or "sickle"-shaped cells. These distorted cells have a shorter lifespan and can block blood flow in small blood vessels, leading to anemia, episodes of severe pain (sickle cell crises), organ damage, and increased risk of infections.

The disease results from the substitution of valine for glutamic acid at the sixth position of the β-globin chain of hemoglobin (HbS). When oxygen levels are low, HbS molecules tend to polymerize, distorting red blood cells into the sickle shape.

Sickle cell anemia is one of the most common hereditary hemoglobinopathies, particularly prevalent among populations of African, Mediterranean, Middle Eastern, and Indian origin. According to the World Health Organization (WHO), millions of people worldwide are affected, with thousands of children born each year carrying the disorder.

This condition not only causes significant morbidity and mortality but also poses a major public health challenge in terms of management and prevention. Advances in genetic counseling, early diagnosis through neonatal screening, and improved therapies such as hydroxyurea, blood transfusion programs, and bone marrow transplantation have improved life expectancy and quality of life for patients.



DO'S AND DON'TS TO CONTROL SICKLE CELL DISEASE

Do's (Recommended Practices)

1. Stay Hydrated: Drink plenty of fluids (8–10 glasses per day) to prevent sickling due to dehydration.
2. Take Medicines Regularly: Follow the prescribed regimen of hydroxyurea, folic acid, penicillin prophylaxis, or other drugs.
3. Eat a Nutritious Diet: Include iron-free but folate-rich foods (green leafy vegetables, pulses, fruits, nuts).
4. Maintain Warmth: Keep the body warm, especially in winter or rainy seasons, as cold exposure can trigger sickling crises.
5. Prevent Infections: Wash hands frequently, maintain hygiene, and avoid close contact with people who are sick.Seek immediate medical attention if fever develops.
6. Regular Health Check-ups: Routine blood counts, liver and kidney function tests, and screening for complications. Monitor growth, vision, and organ health in children.
7. Mild to Moderate Exercise: Light exercise, yoga, and stretching help maintain circulation without over-exertion.
8. Genetic Counseling: Couples with sickle cell trait or disease should seek counseling before marriage or pregnancy.

Don'ts (Things to Avoid)

1. Do Not Skip Medication: Missing hydroxyurea or prophylactic antibiotics increases the risk of crises and infections.
2. Avoid Dehydration: Do not stay in the sun for long without water. Avoid alcohol and excessive caffeine.
3. Avoid Extreme Temperatures: Sudden exposure to cold, rain, or very high heat may trigger painful crises.
4. Do Not Overexert: Strenuous exercise, heavy physical work, or exhaustion can precipitate sickling.
5. Avoid Smoking & Alcohol: These reduce oxygen levels and increase the risk of vaso-occlusion.
6. Avoid High Altitude without Precautions: Places with low oxygen (mountains, unpressurized flights) can worsen symptoms.

7. Do Not Ignore Pain or Fever: Delay in seeking treatment during a crisis or infection may lead to serious complications.
8. Avoid Iron Supplements Unless Prescribed: Many patients have normal or high iron due to repeated transfusions; extra iron may cause toxicity.

SENSITIVE AREAS IN INDIA FOR SICKLE CELL DISEASE

1. **Central India (Highest Burden)**
   Madhya Pradesh – Districts like Jhabua, Alirajpur, Dhar, Khargone, Barwani, Khandwa, and Mandla show very high prevalence.
   Chhattisgarh – Southern and central tribal districts such as Raipur, Durg, Rajnandgaon, Bastar, Dantewada, Kanker, and Bilaspur.
   Maharashtra – Predominantly in Vidarbha and eastern districts: Gadchiroli, Chandrapur, Nagpur, Bhandara, Gondia, Yavatmal, Nandurbar.
2. **Western India**
   Gujarat – High prevalence among tribal communities in Surat, Bharuch, Valsad, Dang, Panchmahal, and Vadodara.
3. **Eastern India**
   Odisha – Strongly endemic in western and southern tribal districts like Sundargarh, Keonjhar, Bolangir, Kalahandi, Koraput, and Kandhamal.
   Jharkhand – Tribal-dominant areas: Ranchi, Gumla, Lohardaga, Simdega, and West Singhbhum.
4. **Southern India**
   Andhra Pradesh & Telangana – Isolated tribal pockets in Adilabad, Warangal, Khammam, and parts of Vishakhapatnam Agency area.
   Tamil Nadu & Kerala – Nilgiri Hills and Attapadi regions among tribal groups (e.g., Todas, Paniyas, Kattunaickans).
5. **Northern India (Low Prevalence but Present in Tribal Pockets)**
   Rajasthan – Southern tribal belt (Banswara, Dungarpur, Udaipur).
   Uttar Pradesh – Some cases in eastern districts but comparatively rare.

GOVERNMENT OF INDIA INITIATIVES FOR SICKLE CELL DISEASE

1. National Health Mission (NHM) Programs:

- Under the National Health Mission, special focus has been given to tribal and high-prevalence districts.
- Screening of school children, adolescents, and antenatal mothers for sickle cell trait and disease is carried out through district health services.
- Counseling services and awareness programs are conducted in collaboration with community health workers (ASHAs, ANMs, Anganwadi).

2. National Sickle Cell Anaemia Control Programme (2016):

- Launched in several tribal states such as Gujarat, Maharashtra, Madhya Pradesh, Odisha, and Chhattisgarh.
- Main activities:
- Community-based screening of tribal populations.
- Distribution of sickle cell cards to carriers and affected individuals.
- Free treatment facilities, including folic acid and hydroxyurea distribution.
- Health education to reduce stigma and increase awareness.

3. National Sickle Cell Anaemia Elimination Mission (2023–2030):

- Announced by the Prime Minister in July 2023 with the goal to eliminate SCD as a public health problem by 2047.

- Targets: Screen 7 crore people (0–40 years) in 278 districts across 17 high-burden states.
- Universal screening in tribal and high-prevalence areas.
- Genetic counseling and premarital counseling to reduce new cases.
- Digital platform for registry and tracking of screened individuals.
- Distribution of Sickle Cell Genetic Status Cards (like blood group cards).
- Integration with Ayushman Bharat – Health & Wellness Centres for treatment and follow-up.

4. Free Treatment and Supportive Care:

- Hydroxyurea tablets and folic acid supplementation provided free of cost in government facilities in tribal districts.
- Blood transfusion facilities strengthened under NHM in district hospitals.
- Early detection programs for newborns and pregnant women to prevent complications.

5. Research and Policy Support:

- Indian Council of Medical Research (ICMR) has established sickle cell research centers in Nagpur, Jabalpur, and Bhubaneswar.
- Studies on prevalence, genetic counseling models, and cost-effective diagnostic kits are supported.
- Ministry of Tribal Affairs collaborates with the Ministry of Health to address SCD in tribal communities.

6. Awareness and Capacity Building:

- Training of healthcare workers (ASHAs, ANMs, nurses, and doctors) on SCD management.
- IEC (Information, Education, and Communication) campaigns in local languages for tribal populations.
- Collaboration with NGOs and community-based organizations for door-to-door awareness.

The Indian government has shifted from small-scale control programs to a comprehensive national mission (2023–2030) focusing on universal screening, free treatment, counseling, and digital monitoring. This represents a strong commitment to eliminating the disease burden in tribal and rural populations by 2047.

MATERIAL & METHOD

For this study we refer government guideline & survey reports released time to time by national as well as state government.

Available Data on Sickle Cell in Balaghat District

- **1. Balaghat Health Department Screening (Recent Local Data)**
- A Daily Bhaskar report indicates that as of mid-2024:
- Over 238,000 individuals in the district were screened for sickle cell anemia.
- Among them, 3,541 were identified as *potentially positive*, and 1,200 confirmed cases were recorded.
- Balaghat now ranks second highest in the state for confirmed cases.
- Key tribal areas such as Baihar, Birsa, Paraswada, Lamta, and Lanji show the greatest disease burden.

2. **A Campaign in 2022 — NRHM Data**

- The National Rural Health Mission (NRHM) initiated a campaign in tribal areas (Baihar, Birsa, Paraswada) where:
- 872 children were diagnosed with SCD in just four days.
- In Paraswada block: of 9,274 tested, 580 were positive.
- In Baihar: 220 positive cases among 5,221 tested.
- In Birsa: 72 positives among 2,682 tested.

(This indicates a prevalence of around 6.2%, 4.2%, and 2.7% respectively in these subregions at that time.)

- Context from *ICMR-Wide* Surveys

While there isn't a dedicated ICMR study for Balaghat, ICMR has conducted broader mapping and research across Madhya Pradesh, which includes the region:

- A 2022 ICMR mapping study reported that six tribes—Pradhan, Panika, Barela, Bhilala, Jharia, and Mehra, located across 15 MP districts, show high incidence of sickle cell disease. Balaghat (not explicitly listed) may share similar tribal dynamics.
- Regionally relevant models, such as the *Sickle Cell Anaemia Control Mission* in Anuppur district, showed—over 18 months (2018–2020):
- 39,421 people screened
- 16.9% had sickle cell trait, 1.98% had disease (779 cases)
- While the above is for Anuppur, it provides a comparable framework for understanding what Balaghat's screening rates (e.g., 1,200 confirmed among ~238k screened = approx. 0.5% disease prevalence) might mean in context.

Table 1: Summary of survey analysis

Source	Covered Area	Screened Population	Confirmed SCD Cases	Prevalence (approx.)
Daily Bhaskar report (2024)	Balaghat district	~238,000	1,200 confirmed	~0.5%
NRHM campaign (2022)	Tribal blocks	~17,200 across 3 blocks	~872 confirmed children	~5% (in those areas)
ICMR mapping (2022)	MP tribal areas	Not specified	Mapping of high-incidence	Tribal connection noted
ICMR model (Anuppur, 2018–2020)	Anuppur district	39,421 screened	779 confirmed (~2%)	SCD 2%; Trait ~17%

For SCD data analysis following sequence of methods is most useful.

(screening → confirmation → quantitation)

Specimen collection: Collect 2–3 mL peripheral venous blood into K_2EDTA tube (neonatal heel-prick dried blood spots are acceptable for NBS workflows).

- Store EDTA blood at 2–8°C and run within 72 hours when possible. For DBS, follow manufacturer drying and storage instructions.

Initial screening tests: Sickling / solubility (Na metabisulphite) test or commercial rapid diagnostic test (Hemo Type SC, Sickle SCAN): fast, low cost; indicates presence/absence of HbS but does not quantify or reliably distinguish trait vs disease.

Record positive/negative: Confirmatory and quantitative tests (gold standard for estimation)

- High-Performance Liquid Chromatography (HPLC) — widely used for quantifying %HbA, %HbA2, %HbF, %HbS and other variants. Preferred for routine quantitation.
- Isoelectric focusing (IEF) / Hemoglobin electrophoresis — useful for confirmation; IEF gives banding but less precise quantitation than HPLC.
- Capillary electrophoresis (CE) — alternative to HPLC with good quantitation.
- Molecular tests (PCR / sequencing) — used for ambiguous cases, prenatal testing, or definitive genotype (e.g., distinguish HbS/β^0 vs HbS/β^+).

SURVEY METHODOLOGY FOR COLLECTION OF SAMPLES FOR SICKLE-CELL SCREENING/STUDY

Following methodogy can be apply to collect the SCD samples.

1. Study design: Community-based cross-sectional survey (or school-based, facility-based — choose depending on target population).

2. Study population & eligibility:

- **Target population**: Residents aged *X* months to *Y* years (specify) in selected communities/schools/clinics.
- **Inclusion criteria:** Individuals who provide informed consent (and assent where applicable), permanent resident or present in the area at time of survey.
- Exclusion criteria: Individuals who decline consent/assent, those with severe acute illness requiring immediate care, or who received transfusion within the last 3 months (transfusion may interfere with Hb testing).

3. Sample size & sampling method:

- **Sampling method:** Multi-stage cluster sampling (clusters = villages/wards/schools) or simple random sampling if sampling frame available. Use probability proportional to size for cluster selection. Within clusters, use household listing or systematic sampling.
- Sample size formula (prevalence study):
- N=Z2.P(1-P)/D2
- Where, Z=1.96 (95%Cl)
- P=anticipated prevalence
- D=desired absolute precision (margin of error)

4. Ethical considerations & consent for sampling:

- Obtain ethics committee/institutional review board approval before fieldwork.
- Prepare participant information sheet in local language(s).
- **Adults:** written informed consent. **Minors:** parental/guardian consent + child assent where age-appropriate.
- Guarantee confidentiality, anonymize samples with unique study IDs, explain benefits (free testing, counseling) and risks (venipuncture discomfort).
- Plan for post-test counseling and referral for those with sickle-cell disease.

5. Field team & training:

- Team composition: 1 team leader, 2 trained phlebotomists, 1 data recorder, 1 counselor/health educator, driver/logistics.
- Train on: informed consent, sample collection (venipuncture/heel/finger), labeling, cold chain, biosafety, data entry, confidentiality, and responding to adverse events.

6. Materials & consumables:

- 3–5 mL plastic vacutainers with K2EDTA (adults); for infants/young children 0.5–2 mL micro-EDTA capillary tubes.
- Tourniquets, disposable needles (21–23G adults, 23–25G pediatric), alcohol swabs, gauze, bandages.
- Pre-printed sample labels with unique IDs, barcode if used.
- Cold boxes with ice packs (maintain 2–8°C), insulated transport containers.
- Biohazard bags, sharps containers, PPE (gloves, masks), forms/tablets for data capture.

7. Sample collection SOP (step-by-step):

- Verify participant ID and consent; assign unique Study ID.
- Record anthropometry and brief clinical history on the data form.
- Prepare equipment on a clean tray; wear gloves.
- For venous blood: disinfect site, perform venipuncture, collect:

- 2–3 mL into K2EDTA tube (adults).
- 1–2 mL (or 0.5–1 mL) for infants as per pediatric guidelines.
- If additional testing required (serology/DNA), collect separate tubes as per lab SOP.
- Gently invert EDTA tube 8–10 times immediately to mix anticoagulant.
- Label tube with Study ID, date and time of collection, collector initials.
- Place tube in upright rack inside cold box (2–8°C) — avoid direct contact with ice packs (use secondary container).
- Observe participant for immediate adverse events; provide care if needed.
- Complete field data form and link sample ID to participant record.
- Dispose sharps in approved container and biohazard waste per regulations.

8. Transport, storage & laboratory receipt:

- Keep samples at 2–8°C (cold chain). Do not freeze EDTA whole blood.
- Transport to testing laboratory daily; minimize time from collection to processing. Aim to process within 48–72 hours for HPLC/ electrophoresis; for molecular tests, follow lab protocol for aliquoting and freezing plasma/packed cells at -20°C / -80°C as required.
- Maintain chain-of-custody log with times, handlers, and condition on arrival.
- On lab receipt, assign lab accession number; log hemolysis or other quality issues.

9. Laboratory testing algorithm:

- Initial screening: CBC (RBC indices), peripheral smear, and sickling test (e.g., sodium metabisulfite) if used for field confirmation.
- Confirmatory testing (recommended): Hb electrophoresis (alkaline & acidic) and/or High Performance Liquid Chromatography (HPLC) — HPLC preferred for reliability and quantification of HbA2/HbF/S.
- Molecular testing: DNA analysis for specific mutations or prenatal confirmation (as indicated).
- Implement internal controls and external quality assessment (EQA).

10. Data collection & management:

- Use structured case report forms (paper or electronic): participant demographics, clinical history (family history, previous transfusions), sample IDs, test results, counseling/referral notes.
- Key variables: StudyID, name (if not anonymized), age, sex, residence, caste/tribe (if relevant), symptoms, transfusion history, family history of sickle cell, sample collection date/time, lab results (CBC, sickling test, HPLC % of HbS, HbF, HbA2), counselor notes.
- Use double data entry or electronic data capture with validation checks. Store data on encrypted server; limit access to authorized personnel.

11. Quality assurance & quality control:

- Field QC: supervisor re-checks 5–10% of forms and sample labels daily.
- Lab QC: run known positive/negative controls with each batch; participate in external proficiency testing.
- Blind re-testing of 5–10% of samples at an independent reference lab.
- Document deviations, sample rejection criteria (e.g., gross hemolysis), and remedial actions.

12. Biosafety & waste disposal:

- Follow standard precautions: gloves, sharps safety, hepatitis B vaccination recommended for staff.
- Dispose sharps in puncture-proof containers; autoclave or incinerate infectious waste per local law.
- Decontaminate surfaces and equipment after use.

13. Post-test counseling & referral:

- Provide pre- and post-test counseling about sickle-cell trait vs disease, implications for health and reproduction.
- For confirmed disease, give written results, counseling, and referral to hematology clinic for baseline care (vaccination, penicillin prophylaxis for children, pain management plan).

- Maintain confidentiality; obtain consent before revealing results to third parties.

14. Data analysis plan (brief):

- Estimate point prevalence (with 95% CI) of sickle-cell trait and disease.
- Stratify by age, sex, community/tribe/caste, and other covariates.
- Use survey analysis methods accounting for clustering and sampling weights (if cluster sampling used).

15. Timeline & logistics (example):

- Preparation & training: 2–4 weeks.
- Field data collection: depends on sample size; e.g., 6–8 weeks for 750 participants with 4 teams.
- Lab testing & quality checks: 4 weeks (concurrent where possible).
- Data cleaning & analysis: 2–4 weeks.

16. Budget considerations (high-level):

- Personnel, transport and cold chain, consumables (vacutainers, needles), lab reagents (HPLC cartridges, control samples), PPE, data capture devices, counseling materials, and contingency.

17. Limitations & mitigating steps:

- Limitation: Transfusion history may mask HbS presence — exclude recent transfusions or note impact.
- Mitigation: Use molecular tests if needed; record transfusion dates.
- Limitation: Cold-chain interruptions → sample hemolysis.
- Mitigation: Plan daily pickups, use validated insulated carriers, and document temperature logs.

EVALUATION

- **Screening** → Sickling test, solubility test, peripheral smear.
- **Confirmatory** → Hemoglobin electrophoresis, HPLC, capillary electrophoresis.
- **Definitive** → Molecular genetic tests (PCR, DNA sequencing).

CURRENT AND FUTURE PROSPECTS OF SICKLE CELL DISEASE

(A)Current Prospects

Improved Diagnosis and Screening: Universal newborn screening programs in many countries enable early identification of affected infants.

- Point-of-care diagnostic kits (e.g., HemoTypeSC™, SickleSCAN™) are increasingly used in low-resource settings.
- High-performance liquid chromatography (HPLC), isoelectric focusing (IEF), and molecular assays provide accurate quantification and confirmation.

Standard Therapies: Hydroxyurea remains the cornerstone of pharmacological therapy, increasing fetal hemoglobin (HbF) levels and reducing crises.

- Blood transfusion programs help prevent stroke and manage severe anemia, though iron overload is a major challenge.
- Supportive care with penicillin prophylaxis, vaccination, and pain management has significantly improved survival rates.

Curative Approaches: Allogeneic hematopoietic stem cell transplantation (HSCT) is currently the only established curative option, though limited by donor availability and risk of complications.

- Advances in conditioning regimens and haploidentical transplantation are expanding accessibility.

Public Health Impact: National programs in India, Africa, and the Middle East are focusing on community screening, genetic counseling, and health-system strengthening.

- WHO and CDC emphasize data collection and public-health surveillance to reduce morbidity and mortality.

(B) Future Prospects

Gene Therapy and Genome Editing: Gene addition: Introduction of functional β-globin genes via lentiviral vectors (e.g., LentiGlobin).

- Gene editing (CRISPR-Cas9, base editing, prime editing): Targeting the *BCL11A* locus or HBG promoters to reactivate HbF, which reduces sickling.
- Approved therapies: In 2023, the FDA approved exagamglogene autotemcel (exa-cel), the first CRISPR-based therapy for SCD, marking a revolutionary step.

Novel Pharmacological Agents: Voxelotor (HbS polymerization inhibitor) and Crizanlizumab (anti-P-selectin antibody reducing vaso-occlusion) have been approved and are expanding therapeutic options.

- Pipeline drugs target inflammation, adhesion, and nitric oxide pathways.

Personalized and Precision Medicine :Integration of genetic modifiers (e.g., HbF persistence genes like *BCL11A* and *HBS1L-MYB*) into predictive models may guide individualized therapy.

- Pharmacogenomics could optimize hydroxyurea response and minimize toxicity.

Expansion of Screening & Prevention : Advances in non-invasive prenatal testing (NIPT) will allow earlier and safer detection of SCD.

- Carrier screening and genetic counseling are expected to reduce disease incidence in high-prevalence regions.

Global Health Perspective: By 2030, WHO projects that integration of curative gene therapies, affordable diagnostics, and community-based programs could drastically reduce SCD burden.

- Partnerships among governments, NGOs, and pharmaceutical companies will be essential to ensure equitable access, especially in low- and middle-income countries**.**

CURRENT SITUATION OF SICKLE-CELL DISEASE (SCD) IN INDIA

(A)National Screening and Prevalence:

- Under the National Sickle Cell Anaemia Elimination Mission (NSCAEM)—launched July 1, 2023—India aims to screen 70 million individuals (7 crore) between ages 0–40 in high-burden and tribal areas by FY 2025–26
- As of July 2025, 6 crore (60 million) people have been screened, with 2.15 lakh diagnosed with sickle-cell disease and 16.7 lakh identified as carriers.
- Additionally, 2.6 crore health cards have been issued to screened individuals for follow-up and monitoring.

(B)State-Level Highlights:

- Odisha leads in case numbers: around 96,080 total SCD cases across India are from Odisha alone
- In Odisha, specifically, screening in the past two years (July 2023–August 2025) covered 46.65 lakh people, identifying 97,501 SCD cases and 4.11 lakh carriers. The state offers free care, ₹500/month transport allowance, and up to ₹10 lakh assistance for pediatric bone marrow transplants
- In Nagpur district (Maharashtra), screening in schools revealed:
- 5.75% of students carried the trait (AS)
- 0.66% had SCD (SS)
- Certain villages like Pusagond showed an alarming 13.51% SS prevalence
- Daga Memorial Women's Hospital, Nagpur screens ~10,000 pregnant women per year, identifying a ~5% carrier rate. They provide treatments including hydroxyurea, and have CSR-backed genetic testing support and financial aid (₹12 lakh for children) for bone marrow transplants

(C)Geographic & Population Trends:

- SCD is predominantly concentrated in tribal populations and central-eastern India, especially in districts of Odisha, Chhattisgarh, Madhya Pradesh, Maharashtra, Gujarat, Jharkhand, Andhra Pradesh, and Tamil Nadu. Some tribal groups have carrier rates as high as 30–40%

- Nationwide, India has one of the highest burdens globally: an estimated 20 million people living with SCD, and 150,000–200,000 SCD births annually
- A significant pediatric health concern: Between 2021–2024, among ~20,000 children suspected of blood disorders, 28.4% tested positive for inherited hemoglobinopathies, including SCD and thalassemia

(D)Diagnostic Access & Affordability:

- Point-of-care test kits have been validated and are now priced at under ₹50 per test, significantly reducing the cost of mass screening (down from ~₹350 initially)
- The NSCAEM integrates with existing health systems (e.g., RBSK, PMSMA) via outreach in schools, anganwadis, mobile units, and primary health centers in targeted districts across the 17 high-prevalence states sickle.
- Infrastructure improvements include health cards, genetic counselling, essential drug availability (like hydroxyurea at primary health facilities), and data tracking through a national portal/app .

CONCLUSION

- The landscape of sickle cell disease management is rapidly evolving. While hydroxyurea, transfusion, and supportive care remain central today, curative strategies such as stem cell transplantation and gene therapy are becoming reality. In the future, precision medicine, wider access to gene editing, and strengthened global health systems promise to transform SCD from a life-limiting disorder into a manageable or even curable condition. India's efforts through the National Sickle Cell Anaemia Elimination Mission are yielding strong progress in screening, diagnosis, and early intervention, especially in tribal and high-burden regions. Yet, the scale of the problem remains massive—with millions affected or at risk, limited access to curative treatments, and significant challenges in care infrastructure.

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