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DIAGNOSIS AND SCREENING PROCESS OF SICKLE CELL ANEMIA IN THE TRIBAL AREA OF SOUTHERN RAJASTHAN

Science

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ABSTRACT

The disease is predominantly seen in the tribal population. Sickle Cell Anemia (SCA) is a major inherited hemoglobinopathy prevalent among several tribal populations in India. Characterized by the presence of abnormal haemoglobin S, it causes red blood cells to assume a sickle shape, leading to chronic anaemia, pain crises, and organ damage. The vertical inheritance (AS to SS) and high rates of consanguineous marriages continue to increase the spread. Most rural health centers still lack testing kits, hydroxyurea supply, and genetic counselling services. This surge underlines the need for aggressive state-wide intervention, with a focus on screening, education, and treatment availability. The study reveals the urgent need for targeted interventions, genetic counseling, and improved healthcare access to mitigate its impact on tribal communities.

KEYWORDS

Sickle Cell Anemia (SCA), Genetic counselling, Tribal Area, Testing kits

INTRODUCTION

SCD, as a genetic condition, is widespread among the tribal population in India where about 1 in 86 births among STs have SCD. A recent 2025 report by the Rajasthan Medical and Health Department has revealed a surge in Sickle Cell Disease cases, with over 10,000 affected individuals documented across nine tribal districts. This sharp increase not only reflects the deep-rooted genetic burden but also highlights the pressing need for systematic, region-specific health interventions. Sickle Cell Anemia (SCA) is a genetically inherited haemoglobin disorder that primarily affects tribal populations across India. The Dungarpur and Banswara districts of southern Rajasthan, with over 80% tribal population—predominantly Bhil, Meena, and Garasia tribes—represent a high-risk zone for SCA. Despite multiple government schemes, the region continues to face underdiagnosis, limited healthcare resources, and traditional beliefs that hamper effective treatment.

Sickle Cell Disease, also known as Sickle Cell Anemia, is an inherited genetic disorder that affects haemoglobin—the protein responsible for carrying oxygen in the blood. Unlike normal disc-shaped red blood cells, SCD patients. These rigid and deformed cells clog blood vessels, leading to complications such as chronic pain, stroke, lung infections, kidney disease, and vision loss.

Epidemiological Background

As per the latest data, 2,980 individuals have tested positive for SCD, while 7,766 have shown early symptoms. The worst-affected districts include Baran, Rajsamand, Chittorgarh, Pali, Sirohi, Dungarpur, Banswara, Pratapgarh, and Udaipur—all regions with a high tribal population. Alarmingly, the report highlights that women are disproportionately affected, with 1,590 of the confirmed cases being female. In response, the health department has issued Genetic Counseling ID Cards (GCID) in pink and blue to affected individuals. Patients have been strongly advised against marrying others with the condition to prevent passing it on to future generations Studies conducted by ICMR and local health departments indicate that the sickle cell trait (AS) is found in up to 18–30% of the tribal population, while 2–6% may be suffering from the homozygous SS disease. Children aged 6–18 years, especially from interior villages, are most at risk. The region suffers from poor connectivity, low literacy, and a high dependence on faith-based healing.

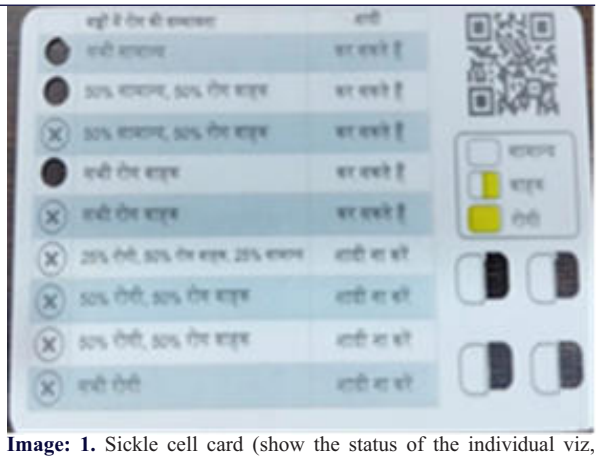

Image: 1. Sickle cell card (show the status of the individual viz, Normal, Carrier or Diseased)

Test Procedure

In government schools, sickle cell Anemia is typically detected through a two-step screening process: initial screening using a solubility test, followed by confirmation with a Point of Care (POC) test or HPLC/Electrophoresis at higher centers for positive cases. This approach is part of the "National Sickle Cell Anaemia Elimination Mission", which aims to screen and manage sickle cell disease in India. In survey people who are identified by pink and blue cards, are called Genetic Counseling ID Cards (GCID).

Image: 2. Sickle cell kit (in-vitro diagnostic kit for quick and accurate identify affected individuals)

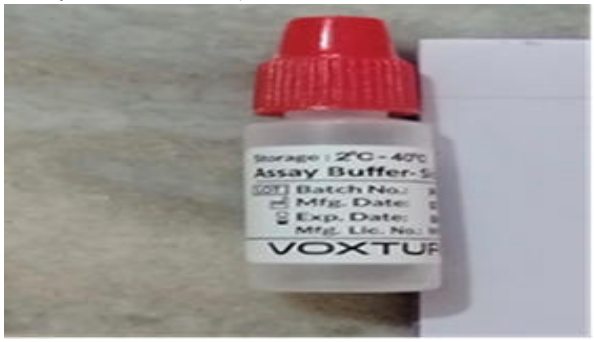

Image: 3. Assay Buffer Solution (used for qualitative detection of different haemoglobin types HbA/HbS/HbC)

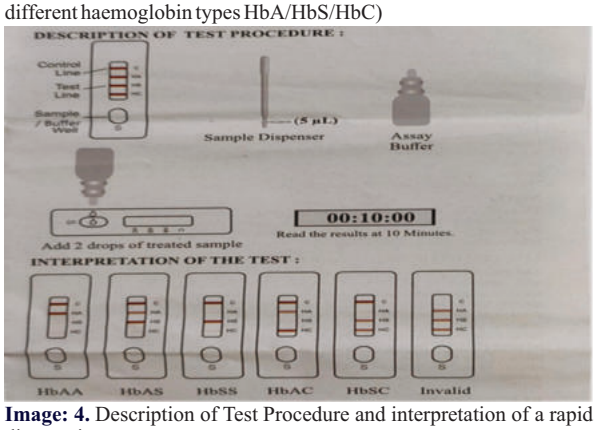

Image: 4. Description of Test Procedure and interpretation of a rapid diagnostic test.

Image: 5. Sickle cell sampling in school (blood sample collection of students)

Image: 6. Sickle Cell Sampling In School (screened for the sickle cell form of haemoglobin)

Image: 7. Sickle Cell Sampling In School Performed By Medical Staff

Existing mechanisms under School Health Programme would be leveraged to ensure SCD-related activities across schools. Parents-teacher meetings would also be utilized as a platform to spread awareness in high-prevalence areas. Those children found to have sickle cell trait will be given plain folic acid through schools and HWC. Also, proper counselling and awareness shall be provided to the families. However, proper treatment guidelines (e.g. hydroxyurea, prophylactic antibiotics, etc.) should be followed up at every stage of the disease.

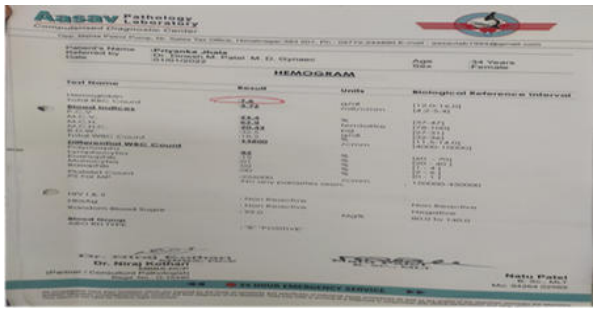

Image: 8. REPORT OF SICKLE CELL (minor) PATIENT IN DUNGARPUR

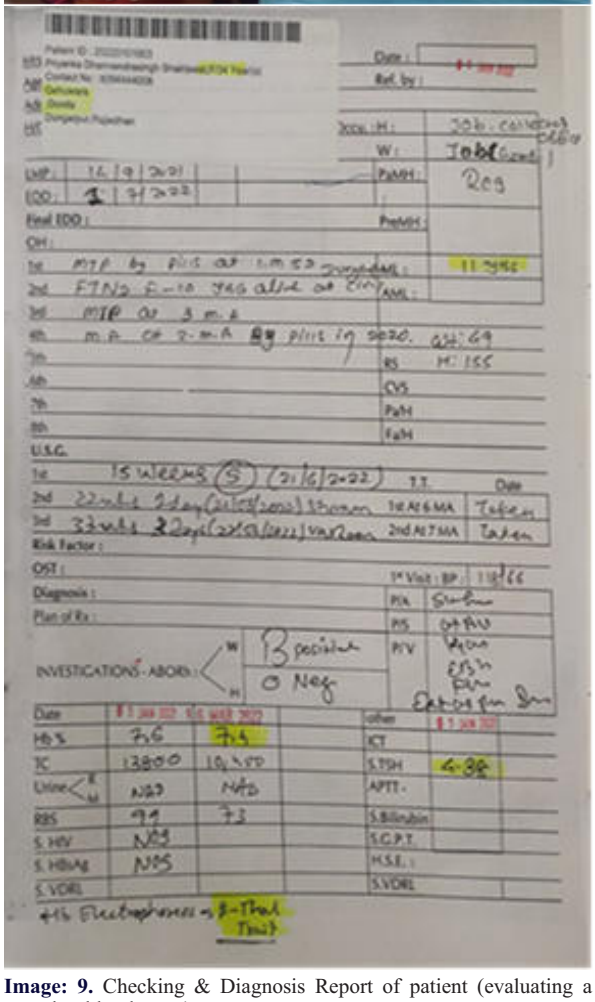

Image: 9. Checking & Diagnosis Report of patient (evaluating a complete blood count)

Clinical Case Overview

Case 1

6-year-old Meena, from Banswara is suffering from sickle cell. Her haemoglobin level in the blood is not able to rise beyond 7-8 mg. She suddenly feels dizzy and falls. The weakness is such that she cannot even stand for long. She has inherited this disease genetically. She is troubled by it.

Case 2

Dinesh from Sajjangarh block is sickle cell positive. He married a girl suffering from sickle cell. Their child falls sick repeatedly and is quite weak. He is now 18 years old and went to Ahmedabad for a check-up when he fell ill. The child was found to be sickle cell positive. After this, the child's parents also got tested and both were found to be positive.

Case 3

Patient from Banswara: Bhil girl, 14 years, Std. 7
Symptoms: Persistent fatigue, yellowing of eyes, severe pain in limbs
History: Both parents AS carriers; three siblings, one also symptomatic
Diagnosis: Confirmed SS via haemoglobin electrophoresis at District Hospital
Treatment: Folic acid and hydration therapy, hydroxyurea prescribed but irregular supply
Challenge: Patient dropped out of school; parents reluctant for continued treatment due to traditional beliefs and travel cost

Case 4

Dungarpur - 2 cases were found (main symptom is Anemia)
Priyanka Shaktawat (DPR)
Roma Rawal, a 20-year girl (Kolkhanda, Dungarpur)

Diagnosis And Screening Gaps

The screening protocol generally follows a two-tier approach. First, blood samples are collected from individuals, with priority given to schoolchildren, pregnant women, and symptomatic individuals. Initial testing is conducted using the solubility test (Sickling test) to detect the presence of abnormal haemoglobin. Individuals who test positive undergo confirmatory testing using haemoglobin electrophoresis or High-Performance Liquid Chromatography (HPLC) to differentiate between carriers (sickle cell trait, AS) and individuals with the disease (sickle cell Anemia, SS).

The primary objectives of these screening programs are to:

- Identify asymptomatic carriers to facilitate genetic counseling.
- Detect affected individuals early to initiate timely clinical management.
- Generate epidemiological data for public health planning in high-burden districts.

Screening activities are often conducted in collaboration with district hospitals, Primary Health Centres (PHCs), mobile health units, and local schools, ensuring accessibility to remote tribal villages.

Haemoglobin electrophoresis and solubility tests are limited to district hospitals. Most PHCs and sub-centers lack trained personnel and diagnostic equipment. Outreach screening camps are irregular and often fail to reach the most remote communities

Cultural And Social Challenges

Tribal populations residing in the southern districts including Udaipur, Banswara, Dungarpur, and Pratapgarh regions report a relatively high prevalence of the disease due to genetic factors and endogamous marriage practices common among certain tribal groups, such as the Bhil and Garasia communities. Illness is often linked to fate, spirits, or ancestral punishment. Social stigma may lead families to hide the disease. Health education in Hindi is often ineffective, highlighting the need for materials in local dialects like Bhili.

Government Initiatives (Rajasthan-specific)

Programs include free screening under the Rajasthan Tribal Sub-Plan and hydroxyurea distribution in district hospitals. However, these are poorly monitored and lack adequate community engagement and follow-up mechanisms. The government has issued an advisory that positive men and women with this disease should not marry each other, as their child could also be positive.

Recommendations For Tribal Regions Like Dungarpur & Banswara

This systematic approach ensures early identification and management of sickle cell cases, especially among vulnerable tribal and rural populations.

- Screening: Mandatory newborn and school-based screening
- Diagnosis: Equip CHCs/PHCs with necessary diagnostic tools
- Awareness: Use local dialects and cultural mediums for communication
- Treatment: Ensure regular hydroxyurea and nutrition support
- Genetic Counseling: Promote community-based centers and premarital screening
- Cultural Inclusion: Involve tribal healers and community leaders in health campaigns

DISCUSSION

The prevalence of the sickle cell trait and disease is alarmingly high in this tribal belt. The lack of awareness, poor transport, and absence of specialized care contribute to the high morbidity. Traditional beliefs often delay diagnosis. Hydroxyurea, though effective, is rarely used due to supply issues and fear of side effects. Genetic counseling and premarital screening are practically non-existent.

CONCLUSION

Sickle Cell Anemia remains a hidden health burden among tribal populations. There is an urgent need for Regular screening programs, Inclusion of genetic counseling in primary healthcare, ensuring consistent drug availability, Awareness campaigns tailored to tribal languages and cultures. Dungarpur and Banswara show a high burden of SCA due to genetic, cultural, and systemic factors. The disease significantly affects education, productivity, and quality of life. A multi-layered, respectful, and community-inclusive approach is essential.

Recommendations

The NSCAEM, launched under the National Health Mission, targets the elimination of sickle cell disease by 2047 through widespread awareness, screening, counselling, and treatment interventions.

- Policy Interventions: Mandatory newborn screening in tribal regions.
- Education: Culturally appropriate educational material in tribal dialects.
- Research: Further genotype-phenotype correlation studies in tribal populations.
- Community Involvement: Engage local leaders and healers in awareness drives.

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