SICKLE CELL ANEMIA AMONG THE PREGNANT WOMEN AND ITS COMPLICATIONS AMONG THE NEONATES: A PROSPECTIVE COHORT STUDY IN SHAHDOL DISTRICT OF MADHYA PRADESH

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Introduction

- Sickle cell anaemia (SCA) is a genetic disorder caused by a mutation in the haemoglobin gene, leading to abnormal red blood cells and various complications. It's prevalent in populations with ancestry from sub-Saharan Africa, India, Saudi Arabia, and Mediterranean countries.
- SCA significantly impacts pregnant women and newborns, increasing risks of complications during pregnancy and adverse outcomes for neonates.
- In India, Madhya Pradesh's tribal population, particularly in districts like Shahdol, has a high prevalence of SCA (up to 35%), making it a critical area for studying the disorder's effects on maternal and neonatal health.

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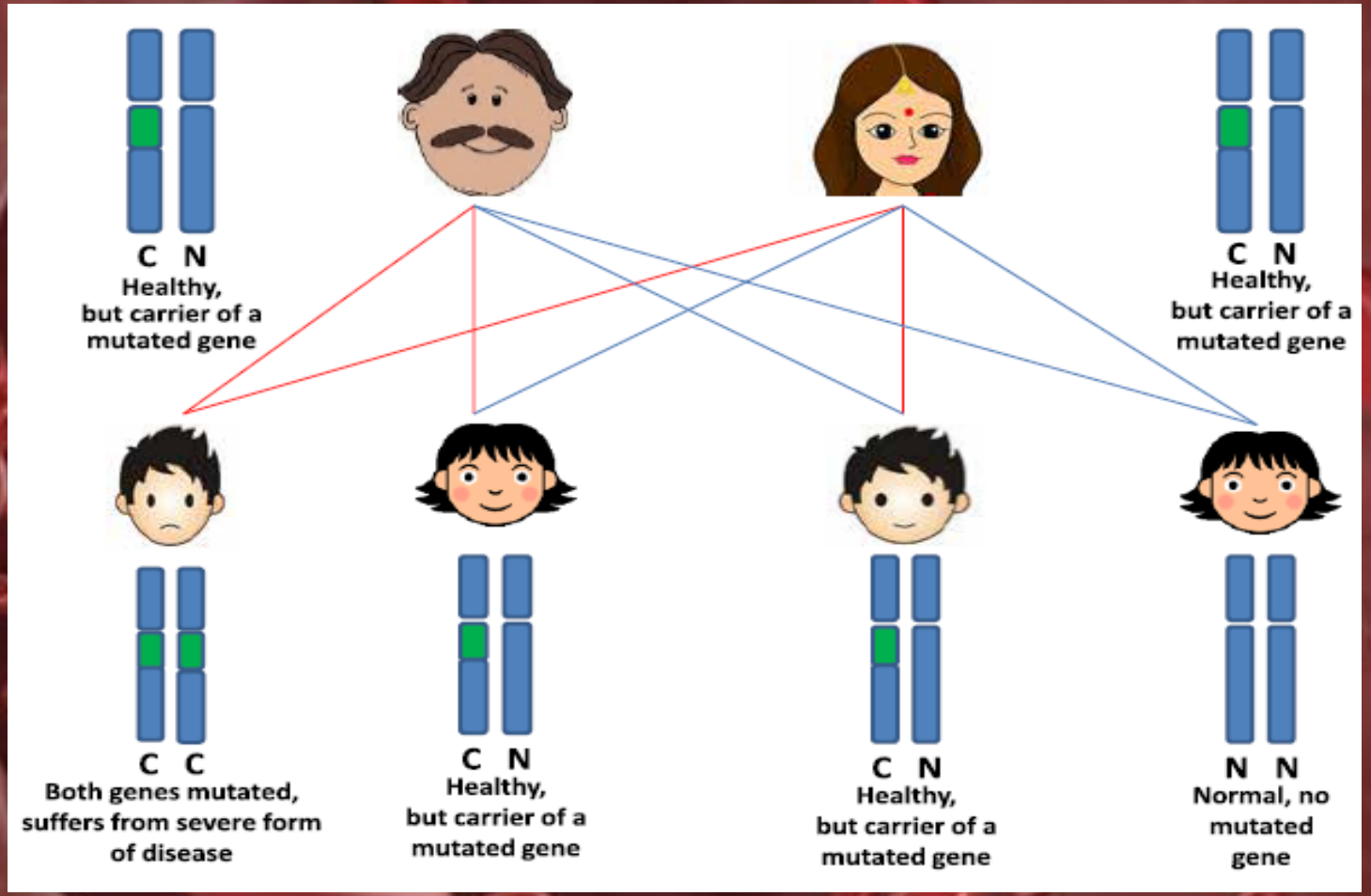

Figure 1: Inheritance and risk of having a child born with Sickle Cell Anemia if parents have Sickle Cell Trait

Literature Review

S.no.	Author, Year	Type of Research	Sample size	Salient features
1.	Surbhi Rajauria, Charu Batra Atreja, Anshu Mujalda, Jagdish Mujalda, Shikha Yadav, and Ramesh K Kundal 2023	Primary	1. Study included 325 pregnant women: 225 with sickle cell disease/trait and 100 controls. 2. SCD group: 38 homozygous (SS) and 187 with sickle cell trait (AS).	The study highlights the significant impact of sickle cell disease (SCD) on pregnancy outcomes, especially in regions like India. It emphasizes higher risks of obstetric complications such as anemia, preterm delivery, and stillbirth among pregnant women with SCD. Maternal morbidity and mortality are notably higher in SCD cases, underscoring the urgent need for improved antenatal and perinatal care. Early detection and comprehensive management strategies are crucial to mitigate adverse effects on maternal and fetal health, improving overall pregnancy outcomes in affected populations.

2.	R. D. Hanmante, S. W. Chopade, K. S. Dhumure, S. Shere, R. S. Bindu 2011	Primary	The sample size for this study is 500 newborns. Sampling Technique: The study used a convenience sampling technique.	This study provides a deep insight into SCD and its detection, notably through neonatal HPLC screening. It emphasizes early diagnosis through simple blood tests and highlights the prevalence of SCD across diverse populations, stressing the necessity of targeted screening. The efficacy of HPLC in identifying carriers is emphasized, alongside the importance of integrating family studies, especially in communities with high consanguinity rates. Early detection and intervention are pivotal in reducing SCD-related morbidity and mortality, underscoring the need for comprehensive screening approaches.

3.	Dr. Mamta Tiwari, Dr. Anurag Pandey, Prof. Aruna Agrwal, Prof. G.P.Dubey	Secondary	Sickle cell disease (SCD) is a global monogenic disorder caused by a β-globin gene mutation, resulting in abnormal hemoglobin (HbS) production. Its pathophysiology involves HbS polymerization, leading to distorted red blood cells and vaso-occlusive events. In India, regions like Madhya Pradesh, Maharashtra, and Odisha have a high SCD burden, especially among tribal populations. Newborn screening programs are vital for early detection, while integrating genetic services into primary healthcare is crucial for quality care. Comprehensive prevention and management strategies are needed to improve health outcomes and life expectancy for affected individuals.

Research Questions

- What are the neonatal complications observed in infants born to mothers with sickle cell anaemia in Shahdol District?
- What current interventions or programs are in place to address sickle cell anaemia in Shahdol District?

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Objectives

- To determine the impact of Sickle Cell Anaemia complications (low birth weight, still birth) on neonates among the pregnant women of Shahdol District of Madhya Pradesh.
- To identify potential interventions or strategies that could be implemented to reduce the prevalence of sickle cell anaemia and its impact on maternal and neonatal mortality in Shahdol district.

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Hypothesis

Hypothesis: Neonates born to mothers with sickle cell anaemia in Shahdol district have a higher incidence of health complications compared to neonates born to mothers without the disease.

Null Hypothesis: There is no significant difference in the incidence of health complications between neonates born to mothers with sickle cell anaemia and those born to mothers without the disease in Shahdol district.

Methodology

- Study Design: Prospective Cohort Analysis of Sickle Cell Anaemia in Pregnancy.
- Setting: The study will be conducted across different blocks of Shahdol district, including: Beohari, Burhar, Jaisinghnagar, Sohagpur and Gohparu. Different sickle cell positive women will be randomly selected from these blocks.
- Study Population: The study will focus on two primary groups:
    1. Pregnant women with Sickle Cell Anaemia
    2. Neonates born to mothers with SCA

Study Duration: The study was conducted over a three-month period

- Sample Size: Based on data from RCH-ANMOL (Reproductive and Child Health - ANM Online) covering the period from 01/04/2022 to 31/03/2024, the study identified 43,774 registered pregnant women across five health blocks: Beohari, Burhar, Jaisinghnagar, Gohparu, and Sohagpur. Among these, 74 women were identified as sickle cell anaemia positive. To ensure a manageable yet representative sample, 25 cases will be randomly selected for in-depth analysis.
- Data Collection Techniques: The study will employ a mixed-methods approach, combining both primary and secondary data sources:

  1. Primary Data (Quantitative): Survey Questionnaire: A structured questionnaire was administered to mothers with SCA at the community level.

  2. Secondary Data: Medical Records: Detailed analysis of hospital and health center records to extract relevant clinical data.

Data Analysis Plan: 1. Data Cleaning and Preparation:

- Rigorous cleaning of the dataset to identify and address missing or erroneous data.
- Preparation of key variables including SCA status, maternal and neonatal mortality rates, demographic characteristics, and other relevant factors.

2. Descriptive Analysis: Comprehensive description of the study population's demographic characteristics.

Findings

- Demographics: The study surveyed 25 women with sickle cell anaemia, predominantly from Scheduled Tribes (48%) and low-income families (80%), across five blocks in Shahdol district.
- Medical History: Half were sickle cell trait carriers, with high rates of pregnancy complications including severe anaemia (56%) and a 20% miscarriage rate.
- Healthcare and Treatment: Despite easy access to healthcare services, there was a lack of specific SCA medication use, limited blood transfusions, and inadequate nutritional guidance.
- Neonatal Outcomes: 20% of babies had low birth weight, 10% were preterm, and 30% experienced health complications after birth.
- Awareness and Access: While all women learned about their condition from healthcare providers, there were significant gaps in genetic counselling, awareness of local SCA programs, and access to specialized care.

Discussion

- Socioeconomic and Demographic Profile: The study found a high prevalence of SCA among socioeconomically disadvantaged women, particularly from Scheduled Tribes, aligning with previous research in India and suggesting both genetic and environmental factors.
- Clinical Manifestations and Pregnancy Complications: High rates of severe anaemia and other complications were observed, consistent with other studies, highlighting the substantial health risks for pregnant women with SCA. The 20% miscarriage rate aligns with known increased reproductive risks.
- Healthcare Access and Disease Management: While healthcare facilities were generally accessible, significant gaps in specialized care and SCA-specific medication use were identified, echoing concerns raised in other studies about comprehensive care in resource-limited settings.
- Neonatal Health Outcomes: The study found significant rates of low birth weight and neonatal complications, consistent with other research, underscoring the intergenerational impact of SCA and the need for specialized neonatal care.
- SCA Awareness and Education: The study revealed a critical need for enhanced awareness and education programs, aligning with recommendations from other studies emphasizing the importance of public health strategies such as genetic counselling.

Conclusion

The survey of women diagnosed with sickle cell anaemia in India highlights significant challenges faced by this vulnerable group, including lack of genetic awareness, suboptimal healthcare quality, and high rates of pregnancy complications. These issues underscore the urgent need for comprehensive interventions.

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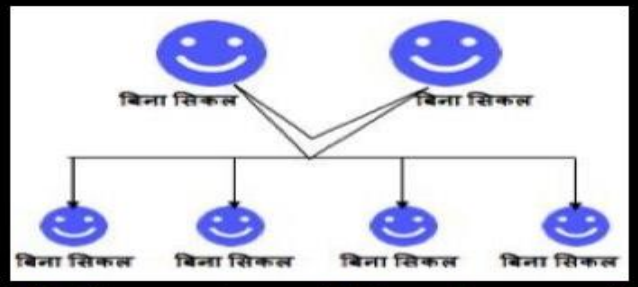
Recommendations

1. Awareness and Education

- Community Education: Implement community-based programs to normalize discussions about sickle cell anaemia, dispel myths, reduce stigma, and encourage open dialogue within affected communities.
- Genetic Counselling: Establish and promote genetic counselling services in healthcare facilities to help individuals understand their genetic status and make informed family planning decisions.

2. Healthcare Infrastructure and Services:

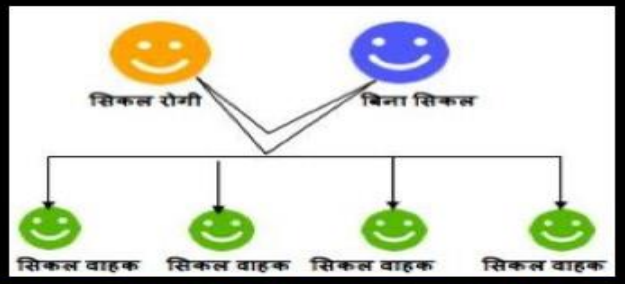
- National Initiatives: Leverage the National Sickle Cell Anaemia Elimination Mission to increase awareness through mass media campaigns and community outreach, improve healthcare infrastructure, and ensure the availability of necessary medications and treatments.
- Training: Train healthcare providers and community health workers in sickle cell anaemia management.



If both parents are AA then there would be:

- 100% chances that in every pregnancy baby would be AA.

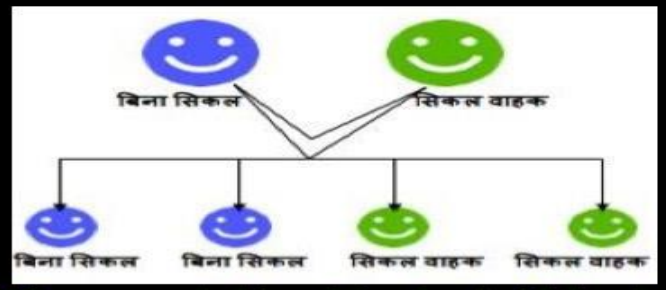
Note: This type of marriage is preferable.



If one parent is SS and one parent is AA then in every pregnancy there would be:

- 100% Chances of having AS

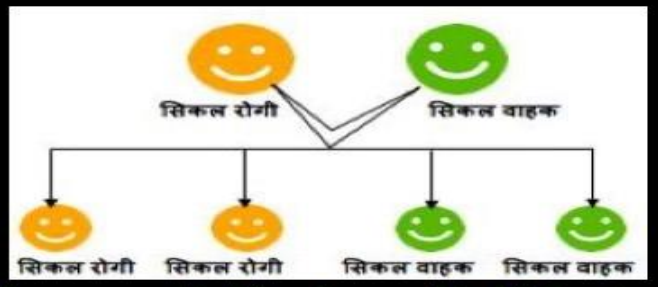
baby Note: This type of marriage is preferable.



If One parent is AA and Another is AS then in every pregnancy there would be:

- 50% chance of having AA baby &,
- 50% Chances of having AS

baby. Note: This type of marriage is preferable.



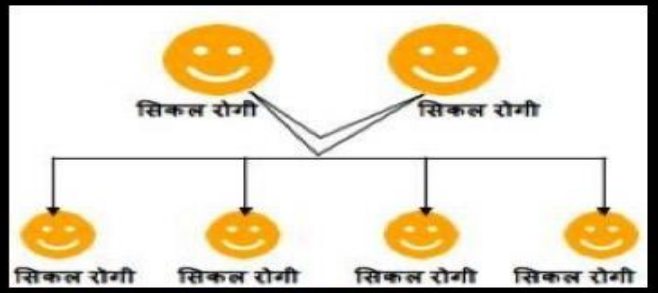
If one parent is SS and second is AS then in every pregnancy there would be :

- 50% chance of having SS baby &,
- 50% chance of having AS baby.

Note: This type of marriage should not be preferred.

If both parents are AS then in every pregnancy there would be :

- 25% Chances of having SS baby,
- 50% chances of having AS baby, &
- 25% chances of having AA baby.



If both parents are SS then:

- It is 100% sure that all their children are going to be SS (Patients).

Note: This type of marriages should be avoided to reduce the burden of the family in the future.

= AA / Normal / Non- Sickle

= AS / Trait / Carrier

= SS / Patient / Diseases

Sickle Kundali for Inheritance of Sickle Cell Genes

Sickle Cell Anaemia Card

मध्यप्रदेश शासन
लोक स्वास्थ्य एवं परिवार कल्याण विभाग
हिमोग्लोबिनोपैथी जेनेटिक काउंसलिंग कार्ड

आई.डी.न.: जिला:
नाम: पति/पिता का नाम:
आयु: लिंग: स्त्री
ब्लड ग्रुप: पता:

टेस्ट रिपोर्ट: सिकलसेल वाहक

पैथोलॉजिस्ट का नाम: हस्ताक्षर:

	बच्चों में रोग की संभावना	शादी?
⊗	सभी सामान्य बच्चे	कर सकते हैं
	50% सामान्य, 50% रोग वाहक बच्चे	कर सकते हैं
⊗	50% सामान्य, 50% रोग वाहक बच्चे	कर सकते हैं
⊗	सभी रोग वाहक बच्चे	कर सकते हैं
⊗	सभी रोग वाहक बच्चे	कर सकते हैं
	25% रोगी, 50% रोग वाहक, 25% सामान्य	सोच लें
⊗	50% रोगी, 50% रोग वाहक बच्चे	उचित नहीं
	50% रोगी, 50% रोग वाहक बच्चे	उचित नहीं
⊗	सभी रोगी बच्चे	उचित नहीं

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	सभी रोगी बच्चे	उचित नहीं

Genetic Counselling Cards to be used to counsel on the inheritance of Sickle Cell-related and other abnormal hemoglobin varients defective genes by children

3. Prenatal Care:

- Guidelines and Monitoring: Develop comprehensive guidelines for managing high-risk pregnancies, including regular monitoring, nutritional counselling, and early intervention for complications.

4. Financial Support:

- Subsidies: Integrate financial support mechanisms into the Sickle Cell Abhiyan to provide subsidies for medications, treatments, and nutritional supplements, alleviating the financial burden on affected individuals and families.

5. Further Research:

- Nationwide Studies: Conduct larger, nationwide studies to gain a comprehensive understanding of the prevalence, challenges, and needs of individuals with sickle cell anaemia across different regions and communities in India. This data will be crucial for shaping effective policies and interventions.

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