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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By

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Under the Supervision and Guidance of

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This is to certify that **Dr. Ushas George** student of **MBA (Health Management)** at **Institute of Health Magement and Research, Bangalore (IIHMR)** had undergone Internship in our Organization from **18th April 2024** to **18th July 2024** and submitted her project report to us on **RMNCH+A+N in Shahdol, Madhya Pradesh** and the same has been found satisfactory.

Her conduct and performance were good during the Internship period.

Regards,

Aanchal Tandon
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DECLARATION BY STUDENT

I hereby declare that this dissertation titled "SICKLE CELL ANEMIA AMONG THE PREGNANT WOMEN AND ITS COMPLICATIONS AMONG THE NEONATES: A PROSPECTIVE COHORT STUDY IN SHAHDOL DISTRICT OF MADHYA PRADESH" is the bonafide record of my original researchwork. I declare that it has not been submitted to any other university or institution for the award of any degree or diploma. Information derived from the published or unpublished work of others has been duly acknowledged in the text.

Signature

Name of the Student: Dr. Ushas George

Date: 05/07/2024

IIHMR UNIVERSITY

CERTIFICATE

This is to certify that the dissertation titled **"SICKLE CELL ANAEMIA AMONG THE PREGNANT WOMEN AND ITS COMPLICATIONS AMONG THE NEONATES: A PROSPECTIVE COHORT STUDY IN SHAHDOL DISTRICT OF MADHYA PRADESH"** is a record of the research work undertaken by Dr. Ushas George in partial fulfillment for the award of the degree of MBA (Hospital and Health Management) from the IIHMR University, Jaipur under my guidance and supervision and her approach to the research study has been sincere, scientific, and an atypical.

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ABSTRACT

Title: Sickle Cell Anaemia among the Pregnant Women and its Complications among the Neonates: a Prospective Cohort Study in Shahdol District of Madhya Pradesh

Author Name: Dr. Ushas George

Advisor Name: Dr. Mamta Chauhan

Keywords: Sickle cell anaemia, maternal health, infant outcomes, tribal healthcare, Madhya Pradesh

Background: Sickle cell anaemia (SCA) poses significant health risks for pregnant women and their newborns, particularly in regions with high prevalence among tribal populations. In India, the Shahdol district of Madhya Pradesh represents an area of concern due to its substantial tribal population and limited healthcare infrastructure

Objectives: 1. 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.

2. 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.

Methodology: Methodology: A three-month prospective cohort study was undertaken on 25 SCA-diagnosed pregnant women drawn from five Shahdol district blocks. Data collected through questionnaires, along with health records and personal interviews, have clearly been studying the socio-economic features, disease manifestations, accessibility to health care, and the outcome of newborns.

Results: The majority of participants were from scheduled tribes (48%) and low-income backgrounds (80% below the poverty threshold). Pregnancy-related complications were common with severe anaemia found in 56% and acute chest syndrome found in 30% of cases. Newborn complications were seen in 30% of births with 20% suffering from low birth weight. Uniquely, there was quite a dramatic lack of specialized medical care, genetic counselling services, and SCA-specific treatments.

Conclusion: Interventions in the case of SCA occurring in pregnancy, such as better prenatal care supplemented by genetic counseling and community education programs, should be comprehensive and integrated. One can conclude that much effort should be directed towards dealing with the issues of the socio-economic factor and improving the quality of health care to increase maternal and neonatal outcomes in regions with higher prevalences of SCA.

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Above all, I am thankful to the Almighty for bestowing upon me the strength, knowledge, and opportunity to undertake and complete this research work.

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ABBREVIATIONS

APGAR	Appearance, Pulse, Grimace, Activity, and Respiration
HPLC	High Performance Liquid Chromatography
ICMR	Indian Council of Medical Research
NICU	Neonatal Intensive Care Unit
NRHM	National Rural Health Mission
SS	Sickle cell
SCA	Sickle Cell Anaemia
SCD	Sickle Cell Disease
WHO	World Health Organization

CHAPTER 1: INTRODUCTION

Health is a cornerstone of human development, influencing every aspect of life from economic productivity to personal well-being. When individuals are healthy, they are better equipped to pursue education, engage in productive work, and contribute to the economy. Healthy populations generally experience higher levels of happiness and well-being, fostering more cohesive and resilient communities. Ensuring good health for all is fundamental to achieving sustainable development goals and enhancing quality of life. Among the most vulnerable populations, pregnant women and newborns require special attention. Pregnant women and newborns are particularly vulnerable and need special care. A mother's health directly impacts her baby's, making maternal and neonatal health a priority for global health efforts. Proper maternal care reduces risks for both mothers and babies during pregnancy and birth. For newborns, early health interventions are crucial for survival and healthy growth.

SCA is an inherited disorder strongly associated with health impact and strongly retarding sustainable development; it is induced by the mutation of only one gene responsible for haemoglobin production, and this creates blood cells with an abnormal form. These cells could assume the 'sickle' shape in case the levels of oxygen are very low or by loss of water. The crescent-shaped cells are rigid and sticky and cause a whole spectrum of pathologies that reduce quality of life and lifespan. These problems include blocked blood vessels, chronic anaemia, severe pain crises, higher risk of infections, and organ damage.

In persons with SCA, the abnormal haemoglobin (Hb-S) leads them to deform into a sickle shape, yet because the red blood cells lose their oxygen, this should clearly not be happening. Rather, they should deform into a round, soft shape. These abnormal cells do not live as long as those that are normal; the body cannot come up with new cells fast enough to substitute the ones that are dying, hence the anaemia. The second major problem is that the sickle cells usually clump together, blocking blood vessels. This can lead to a decrease in the flow of oxygen to parts of the body, painful episodes, organ damage due to lack of blood, and even strokes.(1)

SCA is a lifelong condition that requires continuous medical management and supportive care, placing a significant burden on healthcare systems, particularly in resource-limited settings.

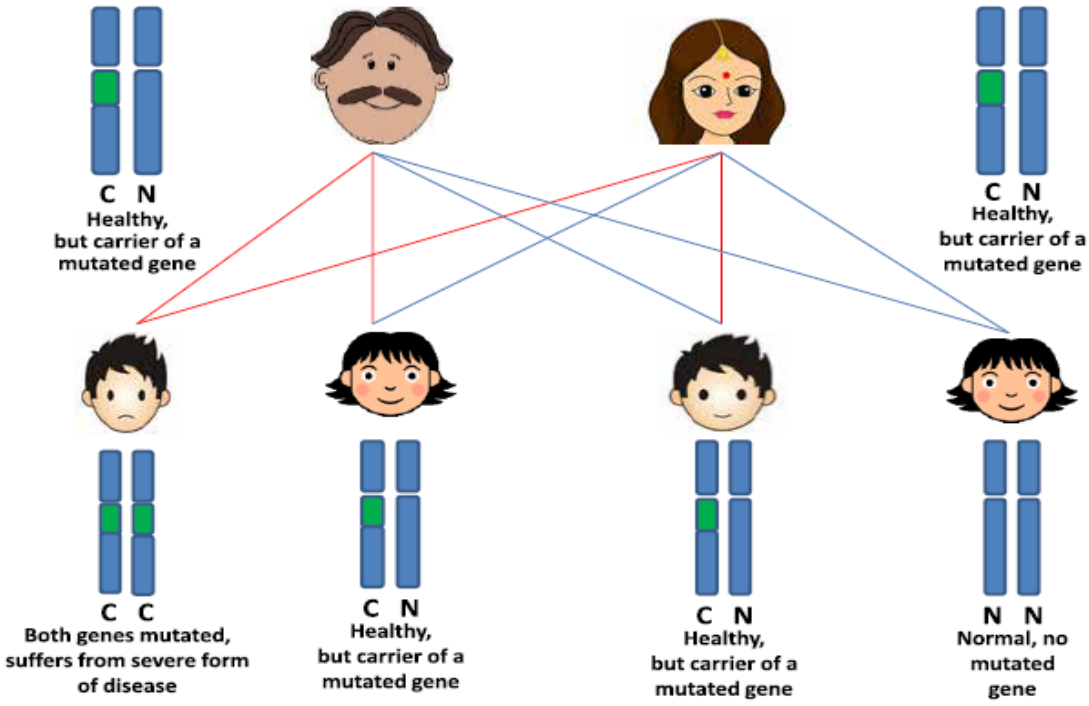


Fig 1.1: Inheritance and risk of having a child born with Sickle Cell Anaemia if parents have Sickle Cell Trait.

Early diagnosis and management for SCA are pertinent, since such conditions can result in fatal complications in early infancy, for instance, the proliferation of bacteraemia and the crisis of acute splenic sequestration.

Sickle cell anaemia is mostly common among global populations with their origin basically in sub-Saharan Africa, India, Saudi Arabia, and Mediterranean countries. Overall, it is estimated that over 300,000 infants are born worldwide per year that carries severe forms of haemoglobin disorders, with registered sickle cell anaemia as part of the major characteristics. However, the burden of SCA continues to be enormous, especially in India and in all parts of Asia, with millions affected and not mitigated greatly in tackling public health challenges.

Genetic diversity in India represents a region with high frequency of sickle cell anaemia, especially among indigenous people. The presence of the illness worsens the existing health inequalities because tribal people normally have a greater distance to travel, which does not enhance their access to health care in remote and poor locations.

Sickle cell anaemia poses a medical risk to a pregnant woman and her baby. Expecting mothers with the condition face an increased chance of pre-eclampsia, poor foetal growth, and early labour. Their newborns are more likely to have a low birth weight, jaundice, and a high-risk probability of early death. Infections are also more prevalent in India, and the anaemia of sickle cell disease renders Indian populations more vulnerable to overwhelming infections which rapidly progress to death, particularly in children. Indeed, in this country, prevalence of sickle cell anaemia is very high in some states and in tribal areas: Madhya Pradesh, Chhattisgarh, Uttar Pradesh, and Gujarat. Some of the tribal populations exhibit rates as high as 30%. The high rates in a large tribal population in Madhya Pradesh are a matter of serious concern. This state harbours districts like Shahdol, Anuppur, and Umaria from where prevalence rates of up to 35% are reported from the tribal belt of the state.

Shahdol district has emerged as a hot spot for research into how this genetic disorder impinges on mothers and babies. It is further disadvantaged by socio-economic factors and basic medical facilities. An area in northeastern Madhya Pradesh, Shahdol is famous for scenic beauty and forests. The total area is 6,205 sq. km., population is 1.064 million and huge tribal population of 44.7 percent. It has been divided into five blocks: Beohari, Jaisinghnagar, Sohagpur, Gohparu, and Burhar, comprising 886 villages with 391 local government units in the form of gram panchayats.

Fig 1.2: Distribution of Blocks of Shahdol District

Such high child and infant mortality prevail in Shahdol due to its unique demography and geography, which increases the difficulty of effective health care delivery. The health statistics of the district are simply amazing. For every 1,000 babies born alive, 43 die as newborns, 72 don't make it to their first birthday, and 80 don't reach age five. These numbers are much worse than India's national averages, showing an urgent need for action.

No doubt, even with major medical breakthroughs, places like Shahdol will always be battling the syndrome of sickle cell anaemia. Management of this condition includes specialized care, such as regular check-ups, control of pain, and sometimes blood transfusions or other treatment measures. Unfortunately, most of the residents of Shahdol do not have access to these services. In most cases, poverty, poor medical facilities or distribution, and ignorance make these people inaccessible to proper medical care.

Objective: Estimate the frequency of sickle cell anaemia among pregnant women in Shahdol and the complications caused by it in newborns. The quantum and implications of the disorder in Shahdol are understood to contribute wider efforts in improving the health of mothers and babies whose environment has been affected by sickle cell anaemia. It is, thus, important that the health needs of this vulnerable group be catered to so that this cycle of poor health can be broken, and overall human development can be enhanced in such communities.

CHAPTER 2: LITERATURE REVIEW

S.no.	Author & Year	Type of research	Sampling Size and Technique	Salient Features
1.	Dipty Jain, Prachi Atmapoojya, Roshan Colah, and Pooja Lodha 2019	Secondary		Although the management of sickle cell disease in pregnancy has improved, specialized care is now recognized as central to its optimal management for affected women and their babies. Effective strategies on the management of sickle cell disease basically incorporate preconception counselling and prenatal screening. Global healthcare disparities are an issue in that the majority of women residing in lower-income areas have no access to the needed treatments. Indeed, ensuring equal access to comprehensive care for all women with SCD during pregnancy remains a key challenge. (2)
2.	APPC Fernandes, JN Januário,	Primary	Sample size: • Total newborns screened:	According to this study, there is a significant SCD burden among children in

	CB Cangussu, DL Macedo, MB Viana Jornal de pediatria 2005		1,833,030 • Children identified with sickle cell disease (SCD): 1,396 • Deaths among children with SCD: 78	Rio de Janeiro, Brazil, with prevalence especially marked in the state of Minas Gerais. It is shown that the mortality is very high with majority of children dying before attaining two years, due to infection as the major cause of death followed by acute splenic sequestration. It indeed stresses the fact that, to lessen the impact of SCD and reduce child mortality from SCD, energetic healthcare infrastructure, including medical training and corresponding public education, is required..(3)
3.	Jeanne A Smith, Mark Espeland, Rita Bellevue, Duane Bands, Audrey K. Brown, Mable Koshy 1996	Primary	Sample size: • Total reported pregnancies: 445 • Pregnancies that proceeded to delivery: 286	It supports ensuring that women with sickle cell who wish to have children receive supportive care, because their rate of complications unrelated to sickle cell disease compares to rates in African American women without sickle cell disease; however, maternal and fetal outcomes are good, with high live birth

				percentages. The risk of having small for gestational age infants is increased, particularly in the presence of the SS genotype, and this calls for proactive management and prompt identification of risk factors such as preeclampsia or an acute anaemic event.(4)
4.	Richard. S. Olney 1999	Review Article		Sickle cell disease presents a complex array of clinical manifestations, necessitating tailored preventive measures based on factors such as genotype and age. Public health strategies, including newborn screening, genetic counseling, and preventive therapies like penicillin prophylaxis, have significantly impacted outcomes in affected populations. (5)
5.	Dipti S. Upadhye, Dipty L. Jain, Yogesh L. Trivedi, Anita H. Nadkarni, Kanjaksha	Primary	Sample size: • 10,181 pregnant women were initially screened • 2,134 newborn	This study in central India identifies infants with sickle cell disease (SCD) through newborn screening and follows them for 3-4 years. It highlights the importance

	Ghosh, Roshan B. Colah 2016		babies were tested • The main cohort consisted of 104 babies with sickle cell anemia (SS) Sampling technique: The study used a targeted screening approach.	of early diagnosis, comprehensive care, and parental education in reducing SCD-related complications. The research emphasizes the need for accessible specialized medical centers and reveals that SCD manifestations can vary in Indian patients. These insights contribute to a better understanding of SCD's progression in this population, potentially improving future research and patient care in India.(6)
6.	Christy Vijay, Nathaniel Fernandes, Jayashree V Kanavi, Teena TM 2022	Primary	The study included 8 pregnant women in total.	This study emphasizes the critical importance of careful management in sickle cell disease (SCD) pregnancies, showing that proper care can significantly reduce risks. Key strategies include thorough prenatal screening, close fetal monitoring, strategic use of cesarean deliveries, and blood transfusions. The findings are particularly relevant for India, highlighting the need for

				specialized SCD pregnancy management and focused maternal-child health programs. This research provides insights that could improve care strategies and outcomes for SCD pregnancies in India.(7)
7.	Gayatri Desai, Ankit Anand, Pankaj Shah, Shobha Shah, Kapilkumar Dave, Hardik Bhatt, Shrey Desai & Dhiren Modi 2017	Primary	The total sample size for this study was 14,640 tribal maternal admissions, of which 10,519 were deliveries. Breaking this down further: • 131 (1.2%) were sickle cell disease (SCD) admissions • 1,645 (15.6%) were sickle cell trait admissions • The remaining 8,743 (83.2%) were non-sickle cell disease admissions The sampling technique can be described as comprehensive or total population sampling	This study highlights the heightened risk of adverse pregnancy outcomes among women with sickle cell disease (SCD), especially prevalent in tribal communities in Gujarat due to high rates of anemia. Urgent improvements in management strategies are needed to address these challenges, emphasizing the importance of advocating for better care for pregnant women with SCD and anemia to enhance maternal health in tribal regions. (8)

			within the specified timeframe and location.	
8.	Roshan B. Colah, Pallavi Mehta and Malay B. Mukherjee 2018	Primary	The total sample size for this study was 18,003 babies who were screened for sickle cell disease (SCD). Breaking this down further: • 2,944 babies were diagnosed as sickle cell carriers • 300 babies were diagnosed with sickle cell disease (SCD) The sampling technique can be described as comprehensive or total population sampling within the context of the screening programs implemented in certain states of India since 2010.	Sickle cell disease (SCD) presents a substantial health challenge in India, particularly among tribal populations. Tailored management strategies are essential due to regional variations in clinical manifestations. Pilot newborn screening programs highlight the need for early intervention, but scaling up and sustaining such efforts are vital. The recent establishment of national guidelines for a Hemoglobinopathy Program signifies progress toward improved SCD management nationwide. (9)
9.	Neema Acharya, A Kriplani, C. Hariharan 2013	Secondary	The study had a total sample size of 50, which included both cases and controls. The sampling was	Sickle cell disease presents significant challenges in pregnancy, especially in high-prevalence areas like

			done in two parts: Retrospective component: Studied pregnant females admitted to the obstetrics ward of AVBRH and its peripheral sub-centers from January to June 2009. Previous medical records and case files were examined. All sickling positive women were included as cases. Prospective component: Studied pregnant women admitted in July and August 2009. All consenting pregnant women were screened for sickle cell disease (AS & SS character) using the sickling test. Positive cases were included in the study. Positive cases underwent Hb electrophoresis to differentiate sickle cell anemia (SS) from	central India. Maternal complications, like vaso-occlusive crises and anemia, lead to increased preterm births and cesarean deliveries. Fetal complications, including growth restriction and low APGAR scores, require NICU admissions. Enhanced antenatal care and hematologic support are vital for reducing maternal risks. Further extensive research is essential to enhance outcomes for both mothers and infants affected by sickle cell disease. (10)

			sickle cell trait (AS). Controls: An equal number of controls, negative for sickling and comparable with cases, were randomly recruited into the study.	
10.	Surbhi Rajauria, Charu Batra Atreja, Anshu Mujalda, Jagdish Mujalda, Shikha Yadav, and Ramesh K Kundal 2023	Primary	The total sample size for this study was 325 pregnant women, divided into two groups: Sickle Cell Disease (SCD) group: 225 pregnant women 38 (16.89%) with homozygous sickle cell disease (SS group) 187 (83.11%) with sickle cell trait (AS group) Control group: 100 pregnant women with normal hemoglobin (AA genotype)	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. (11)

11.	Rahi S. Modi, Srushti S. Patel, Dipti A. Modi, Heena Talesara 2021	Primary	The total sample size for this study was 43 pregnant women with Sickle Cell Disease (SCD).	Pregnancy in women with sickle cell disease poses significant risks, demanding proactive screening in public health sectors, especially among scheduled tribes. Improved preconception counselling, antenatal care, complication management, and timely referrals are vital for better outcomes. This study emphasizes the urgent need for comprehensive strategies to address these challenges and enhance care for pregnant women with sickle cell disease, aiming to reduce adverse outcomes. (12)
12.	Ranbir S. Balgir, 2014	Primary	The total sample size for this study was 383 couples, including their offspring. These were divided into two groups: 1. Case group: 183 couples with different sickle cell disorders 2. Control group:	Sickle cell disorders are a major genetic health issue in India, particularly in regions like Madhya Pradesh. This research highlights the reproductive challenges faced by carrier couples, stressing the importance of genetic counselling and early detection methods such as carrier screening

			200 normal couples The researchers used consecutive sampling, including all eligible couples referred to the testing center during the study period.	and prenatal testing. These strategies are crucial for preventing affected births, improving health outcomes, and benefiting both affected families and the global health community. Proactive measures in prevention and early intervention are essential to tackle this public health challenge and ensure healthier future generations.(13)
13.	Yazdi Italia, Lakshmanan Krishnamurti, Vishal Mehta, Bhavesh Raicha, Khushnooma Italia, Pallavi Mehta, Kanjaksha Ghosh, Roshan Colah, 2015	Primary	The study screened a total of 5,467 newborn babies.	Sickle cell disease poses significant global health risks, particularly in high-prevalence areas like India. A study in rural south Gujarat shows that newborn screening programs can enable early detection and treatment, but challenges in follow-up care highlight the need for integrated healthcare systems to manage SCD effectively in resource-limited settings.(14)
14.	Deepak Saxena, Sandul	Review Article		Sickle Cell Disease is a major health problem worldwide but even more

	Yasobant, Mahaveer Golechha, 2017			so in high-prevalence areas like India. The huge thrust given to screening notwithstanding, standardization of care is challenging, and heterogeneity in prevalence observed across tribal groups from Gujarat mandates specially targeted interventions with continued research support. The establishment of registries, investigation into genetic factors, and understanding morbidity profiles underpin the need to improve SCD management in India.(15)
15.	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 an insight at deep detection regarding SCD, mainly through neonatal HPLC screening, which underlines early diagnosis through simple blood tests and the need for targeted screening with its wide prevalence across diverse populations. It shows the efficiency of HPLC in detecting carriers and

				family studies, especially where consanguinity rates are high in some communities. Comprehensive early detection and treatment allay the problem of the high rates of morbidity and mortality due to SCD, and thus, comprehensive screening strategies are important.(16)
16.	2019	Primary		The study emphasizes the significant impact of sickle cell disorders on reproductive outcomes and neonatal/infant mortality rates in Madhya Pradesh, India. It highlights heightened reproductive wastage, including abortions, stillbirths, and neonatal deaths, among sickle cell carrier couples compared to normal controls. The trend of increased defective offspring in affected families underscores the need for genetic counseling and intervention. Addressing hereditary factors alongside non-genetic

				variables is crucial to mitigate the burden of sickle cell disorders and reduce mortality rates. Prevention, early detection, and education efforts are essential to combat these genetic challenges and improve reproductive health outcomes. (17)
17.	Anupama A. Manjula1, Mary Tresa 2017	Primary	The sample size for this study is 70 women. The sampling technique appears to be a purposive sampling method.	This study highlights the significant impact of sickle cell anaemia (SCA) on pregnancy outcomes in Kerala, India, with notable risks including sickle cell crisis and obstetric complications. While no significant differences were found between SCA cases and controls in outcomes, further evaluation of complications is warranted. Early and comprehensive management by a multidisciplinary team may aid in mitigating risks associated with SCA in pregnancy, potentially improving outcomes for affected individuals. (18)

18.	Roshan B. Colah, Malay B. Mukherjee, Snehal Martin, Kanjaksha Ghosh, 2015	Review Article		Sickle cell disease (SCD) is a global monogenic disorder, first described in the early 20th century. India, with its significant tribal populations, faces a substantial SCD burden, necessitating targeted screening efforts. Recent initiatives like newborn screening programs are crucial for early identification. Co-inheritance with β-thalassemia complicates the disease profile. Challenges in delivering healthcare to tribal populations persist, but innovative models show promise. Understanding maternal and perinatal outcomes remains a research focus, with prenatal diagnosis offering important options. Integration of genetic services into primary healthcare is vital, with initiatives by organizations like ICMR and NRHM facilitating equitable access to care.(19)

19.	Dr. Mamta Tiwari, Dr. Anurag Pandey, Prof. Aruna Agrwal, Prof. G.P.Dubey 2015	Primary		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. (20)
20.	Bhavya Doshi, Madhuri A	Secondary Case Report	The case description provided is of a single patient (a 23-year-old	Pregnancy in women with sickle cell disease (SCD) carries high risks due to

	Mehendale, Arun H Nayak, Archana A Bhosale, Snehal Mulik 2021		primigravida with sickle cell disease)	complications like anemia and exacerbated physiological changes. Despite improved management with interventions such as prophylactic transfusions, maternal and fetal complications persist. A multidisciplinary approach with experienced hematologists and obstetricians is crucial for better outcomes. Preconception counseling and thorough prenatal care are vital for mitigating risks and improving pregnancy outcomes in SCD patients. (21)

CHAPTER 3: METHODOLOGY

Research Questions: 1. What are the neonatal complications observed in infants born to mothers with sickle cell anaemia in Shahdol District?

2. What current interventions or programs are in place to address sickle cell anaemia in Shahdol District?

Objectives: 1. 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.

2. 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.

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.

Study Design: Prospective Cohort Analysis of Sickle Cell Anaemia in Pregnancy. This cohort study aims to investigate the prevalence and impact of Sickle Cell Anaemia (SCA) among pregnant women and their neonates in the Shahdol district.

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: This cohort will be identified through medical records, diagnostic tests, or documented medical history. The study will explore their health outcomes, complications, and healthcare experiences.

2. Neonates born to mothers with SCA: This group will be closely monitored for any complications or health issues potentially related to maternal SCA.

Study Duration: The study was conducted over a three-month period, allowing for comprehensive data collection and analysis from various public health facilities and community health centres.

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. Thereby gathered information on their experiences, challenges, and health outcomes.

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:
    - an overview of the demographic characteristics within the study population
3. Outcome Assessment: The relationship that will exist between maternal SCA and neonatal complications will be evaluated.

4. Interpretation and Reporting:

    - Interpretation of results in reference to the existing literature and clinical relevance.
    - Discuss implications for healthcare policy, clinical practice, and future research.
    - To collate an exhaustive report detailing the methods, results, and conclusion of this study.

The expanded study design would be more comprehensive to look into the prevalence and its effects on pregnancy with sickle cell anaemia in the Shahdol district. The study would allow for different health levels and, using a mixed-method approach, give a sensitive understanding of this important health problem.

CHAPTER 4: RESULTS

The survey in question focused on 25 women who have been diagnosed with sickle cell anaemia. The demographic information includes:

1. Geographic Distribution:

   The participants were distributed in five different blocks: Beohari-3 women, Burhar-4 women, Gohparu-7 women, Jaisinghnagar-6, and Sohagpur-5. Inferences drawn from this information is that Gohparu and Jaisinghnagar had the highest representation in this survey.

S.No.	Block Name	No. Of Participants
1.	Beohari	3
2.	Burhar	4
3.	Gohparu	7
4.	Jaisinghnagar	6
5.	Sohagpur	5
	Total	25

a) Caste Composition: The women belonged to three main caste categories:

- Other Backward Classes (OBC) (20%)
- Scheduled Castes (SC) (32%)
- Scheduled Tribes (ST) (48%)

Notably, the majority (48%) were from Scheduled Tribes. This could indicate a higher prevalence of sickle cell anaemia among ST communities in the region, or it might reflect the demographic makeup of the area.

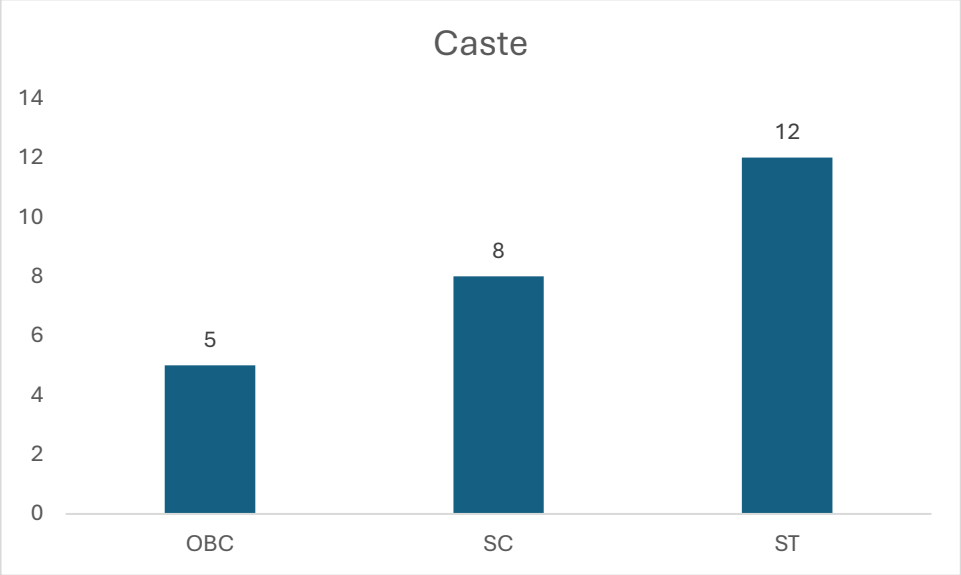


Fig 4.1: Caste wise distribution of Respondents

b) Economic Status: Eighty percent of the women who participated in the survey had a family income of below poverty line indicating that may be sickle cell anemia is a disease that is more prevalent in economically poorer sections of the society, or women with a lower income have responded more to stimulate the survey.

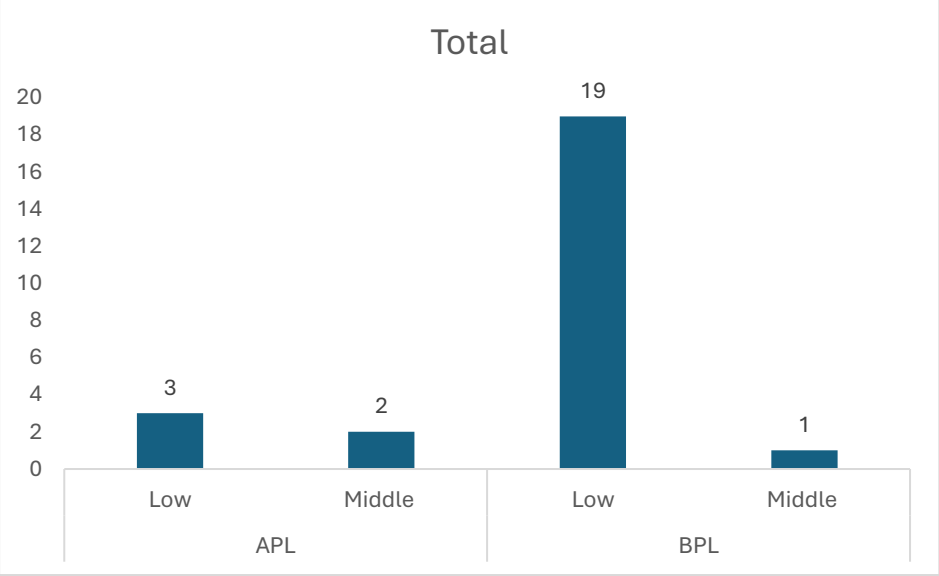


Fig4.2: Distribution of Socio-economic Status

c) Educational Background: The educational attainment of the participants varied:

- Primary education: More than 15% (4 women)

- Secondary education: 60% (15 women)

- Higher education: 20% (5 women)

This distribution shows that most of the women had at least some secondary education, which is a positive indicator. However, the low percentage of women with only primary education might suggest that those with less education were underrepresented in the survey or had less access to medical diagnosis.

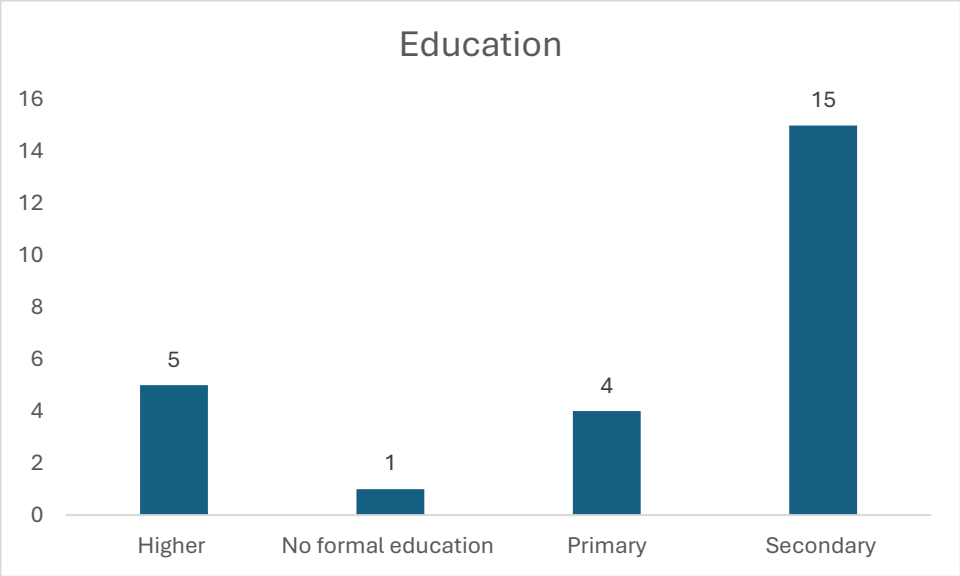


Fig 4.3 Education distribution of Respondents

d) Age Range: The participants ranged from 18 to 55 years old. This wide age span allows for a comprehensive view of how sickle cell anaemia affects women across different life stages.

e) Socioeconomic Status: An overwhelming majority (88%) of the women were classified as belonging to the lower middle class. This aligns with the high percentage of BPL ration card holders and suggests that the disease may have significant economic implications for the affected families.

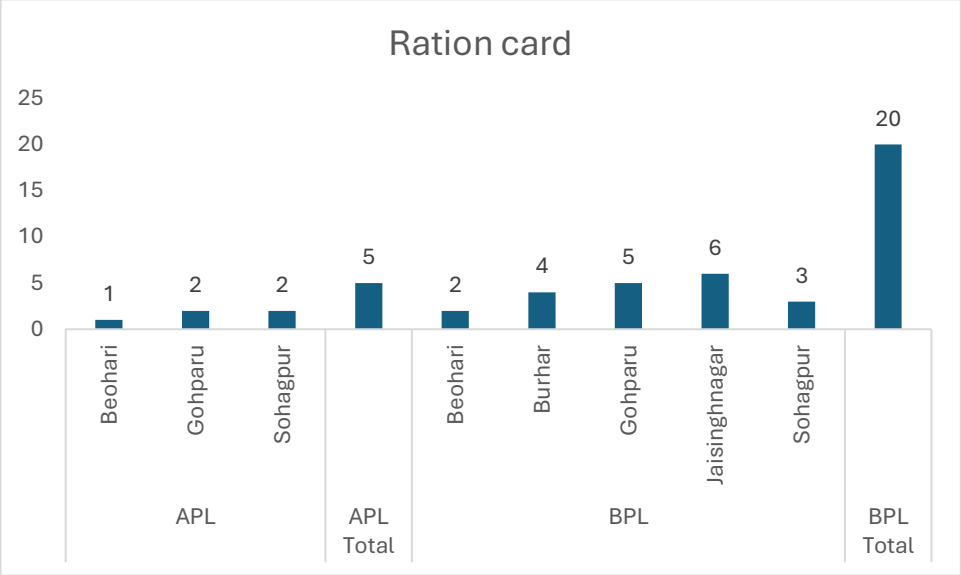


Fig 4.4: Ration Card distribution of Blocks

2. Regarding the medical history of positive sickle cell anaemia women,

a) Diagnosis and Genetic Status: The women were diagnosed with sickle cell anaemia 2-3 years prior to the survey.

- Genetic status breakdown: - Carriers (sickle cell trait): 50% (13 women)
  - Unknown genotype: 35% (9 women)
  - Sickle cell disease: 10% (3 women)

  The high percentage of women unaware of their genotype (35%) suggests a need for improved genetic counselling and testing services.

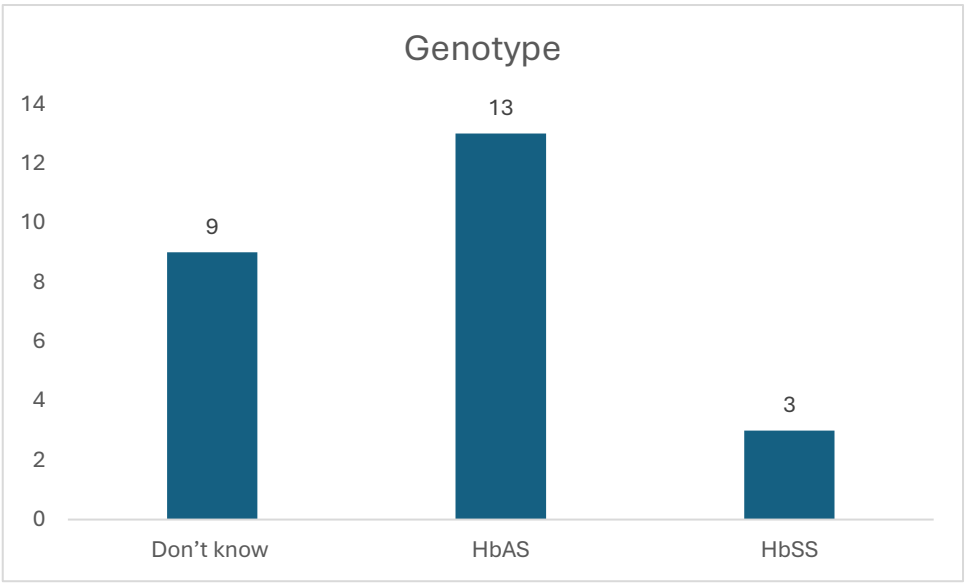


Fig 4.5: Distribution of various Genotype

b) Obstetric History: Previous pregnancies- 65%

First time pregnancies: 35% (9 women)

This distribution makes the comparison among experience possible for those women with and without pregnancies.

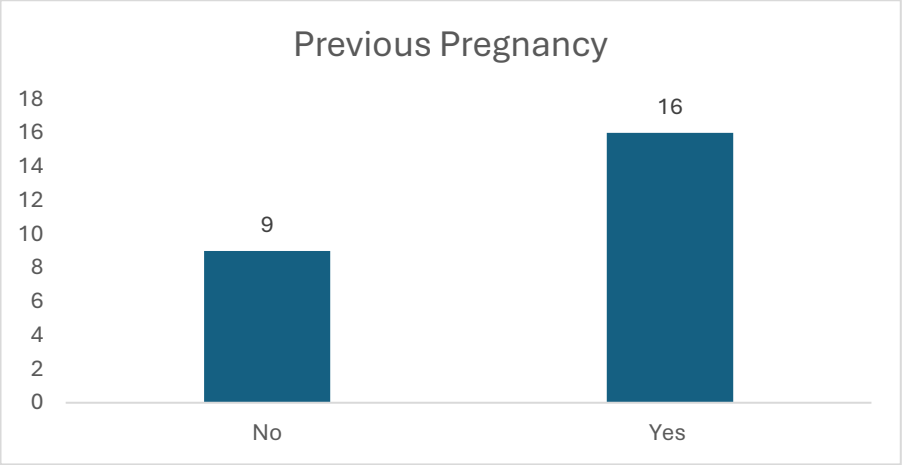


Fig 4.6: Distribution of Previous pregnancy of Respondents

c) Pregnancy Complications: Vaso-occlusive crisis or preeclampsia, known to have a high prevalence in the condition of sickle cell anaemia during pregnancy, did not surprisingly occur in any respondent. Other complications that were prevalent:

• Severe anaemia: 56% (14 women), Acute chest syndrome: approximately 30% (7 females).Other complications, including fatigue and pain: 65% of cases (16 women)

These high rates of complications also present an important need for specialized care for pregnant women with sickle cell anaemia or trait.

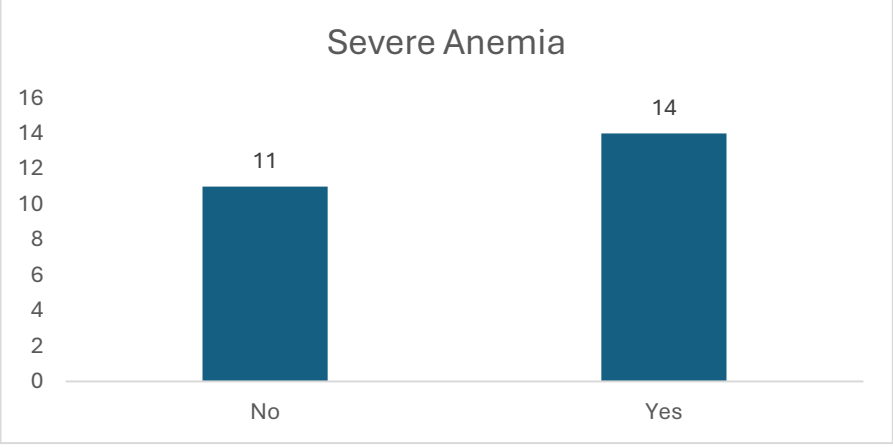


Fig 4.7: Distribution Of Severe Anaemia Complications of Respondents

d) Pregnancy Outcome: Rate of Miscarriage: Around 20% (5 women). This is a really troubling rate and shows high susceptibility to the complications of sickle cell anaemia during pregnancy.

e) Prenatal Education and Counselling: Only 40% (10 women) had had counselling or education about possible risks and complications. This low number suggests a huge gap in terms of prenatal care and education for women with sickle cell anaemia.

3. Let's delve into the health and lifestyle aspects of the women with sickle cell anaemia in this study:

a) Medication and Treatment: It is surprising to note that none of the women in the study were on medication specifically needed for sickle cell anaemia. This lack of treatment may somehow contribute to the high rate of complications noted because;

b) Blood Transfusion: Blood transfusions in pregnancy were given to only 03 women, a tenth of the total. However, since anaemia, described earlier, was grossly 56%, the transfusion rate was less and apparently calls for a try at explanation.

c) Nutritional Counselling: Sixty-five percent (16 women) did not undergo nutrition and dietary counselling during pregnancy. This is quite telling since proper nutrition is very important for the management of sickle cell anaemia and when it comes to supporting a pregnancy.

d) Nutritional Supplements : On the brighter side, 24 of these women or 95% had nutritional supplements, such as folic acid and iron. This is quite a high rate of having the supplements. The supplements are crucial primarily for women with sickle cell anemia when pregnant. On the other hand, the supplements will become ineffective if there is no guidance that should be given regarding food and diet.

e) Common Symptoms : The symptoms that the women experienced include:

- Fatigue: 80% (20 women) was the most common symptom probably affecting daily life remarkably.

- Pain crisis: 40% (10 women) stands as a hallmark symptom of the disease and often heralds severe bouts..
    - Shortness of breath: 44% (11 women) - This could be related to anaemia or other complications.
    - Swelling of hands and feet: 20% (5 women) - While less common, this can be uncomfortable and may indicate circulatory issues.

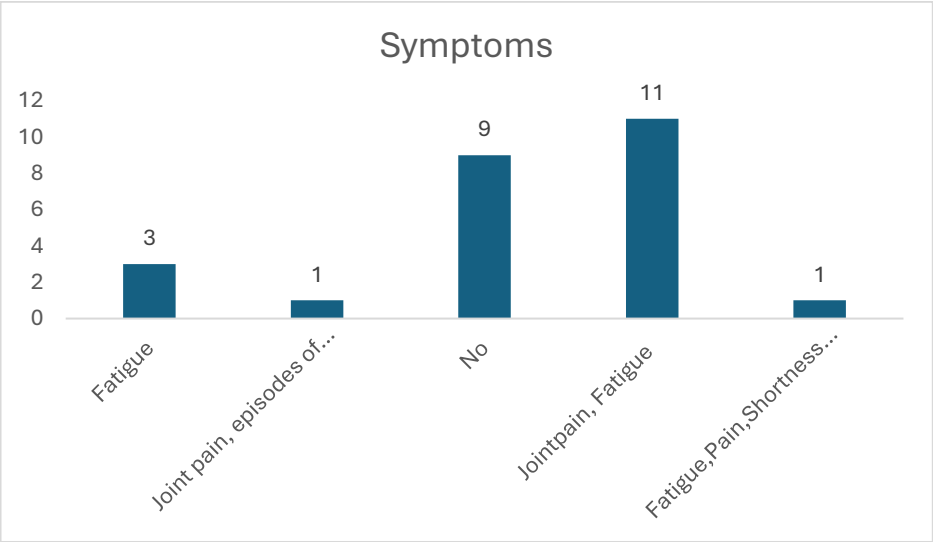


Fig 4.8: Symptoms of the Respondents

4. This neonatal information provides crucial insights into the outcomes for babies born to mothers with sickle cell anaemia. Let's break down and expand on these findings:

a) Birth Weight: Approximately 20% of the babies were born with low birth weight, defined as less than 2.5 kg. This is a significant percentage and higher than the global average, which is typically around 15%.

b) Preterm Births: About 10% were born preterm. While this is lower than might be expected given the mothers' health conditions, it's still a concern. Preterm birth is associated with various complications and can lead to long-term health and developmental issues.

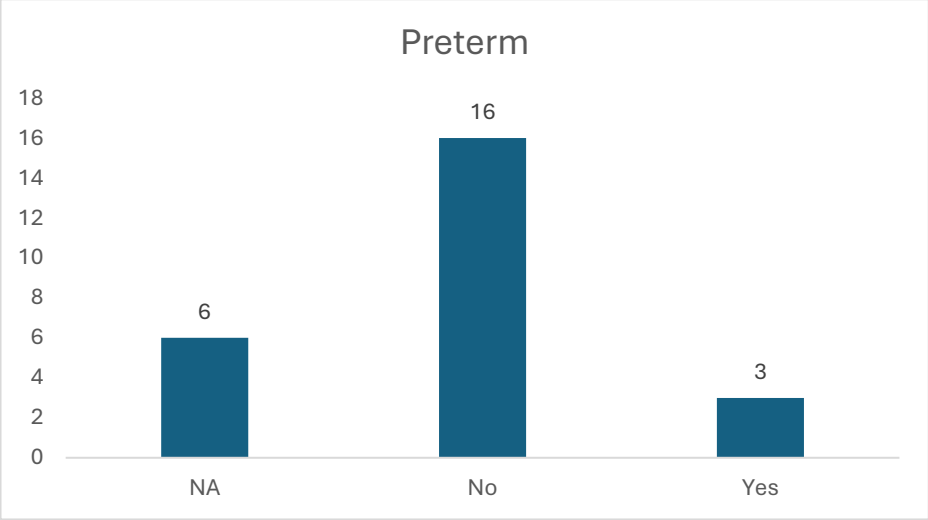


Fig 4.9: Preterm births of the Neonates born to the Sickle Cell Positive mothers

c) Neonatal Health Complications: A substantial 30% experienced health complications after birth. These included: Jaundice, Low birth weight (as mentioned earlier), Neonatal sepsis, etc.

This high rate of complications underscores the increased health risks for babies born to mothers with sickle cell anaemia.

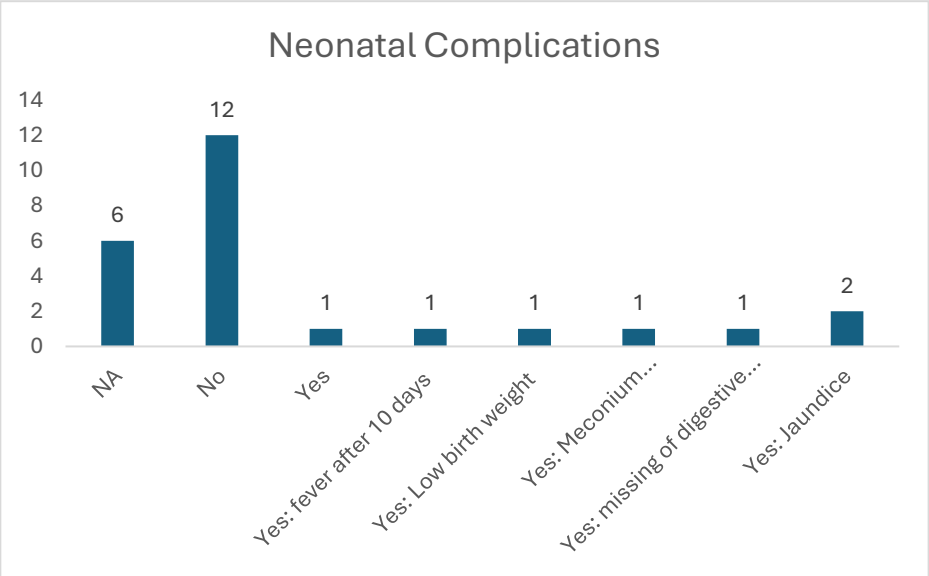


Fig 4.10: Neonatal Complications

5. This data eloquently speaks of the awareness and education landscape surrounding sickle cell anaemia (SCA) among the interviewed women. Here, we discuss and elaborate on these results.

a) Healthcare Provider as Primary Information Source: 100% of the women learned about their sickle cell anaemia status from healthcare providers. This is a positive finding because this means that these women did have access to healthcare services, which can be able to diagnose SCA. The healthcare providers actively communicate with patients the diagnosis of various conditions and diseases.

The following were reported by about 30% of the women to have received this information through community health workers. This only points to an important role that these community health workers are performing in the dissemination of health-related information. Community health programs are there in the area and still high chances of further enhancing the role of community health workers in SCA education and support.

b) Awareness of local Interventions and programs: Only about 8% (2 women) were aware of Interventions or programs for SCA in their area.

c) No Genetic Counselling: Interestingly, nobody among the women got any form of genetic counselling, while this remains a very critical gap, considering the role of genetic counselling in helping individuals to understand their genetic status and its implications, as well as assisting them in the decisions regarding family planning and providing information on potential health risks and management.

d) Perceived Need for Additional Awareness and Education: Nearly universally, the women felt more awareness and educational programs regarding SCA were needed in their community.

These are, therefore, points that point to the multipronged approach of making improvements in SCA care and awareness among health providers, the community health workers, public health officials, and the affected individuals. Correcting these gaps could lead to an improvement in quality of life and health outcomes of people affected with SCA in that community.

6. That renders revealing information on healthcare access and needs of the women suffering from sickle cell anaemia in the area of the study. Let's dissect and elaborate these findings:

a) Location and Accessibility of Health Facilities: Nearly 50% (13 women) reported 1 km distance from their residence to the health facility. A striking 95% (24 women) responded in the affirmative to easy access for availing routine checkup and treatment for the management of treatment in SCA.

b) Health Care Access Barriers: They reported no such identified significant barriers to any them health care services

c) Desired Health Care Improvements: Women reported good access but several desires for improved care.

• Facilities for Better Health Care: 90% (23 women)- the figure is high, indicating that though facilities are accessible, quality or capabilities are not up to the mark.

• Access to Specialized Care: 64% (16 women)- This seems to signify that ailing from SCA is a disease that definitely requires specialized care, which might not be got in general health facilities.

• Nutritional Support: 44% (11 women)—This supports earlier findings reflecting the absence of nutritional counselling and underlines diets in the management of SCA

• Genetic Counselling: Few women suggested this. With a few suggestions, it does fit with the above that none had genetic counselling, indicating a large gap in care.

d) Sickle Cell Anaemia Card: Only one person had a sickle cell anaemia card.

Therefore, these findings suggest that while basic access to healthcare was good in this community, there is significant room for improvement in the current quality and comprehensiveness of SCA care. Addressing these gaps should substantially improve management and quality of life for the affected women in this community.

CHAPTER:5 DISCUSSION

Our results on SCA in pregnant women of the Shahdol district of Madhya Pradesh, India, bring to light some critical inputs regarding the complex issues faced by this vulnerable population. In the present research, 25 cases diagnosed as SCA were taken to query into the socio-economic, clinical, and healthcare-related attributes in the management of this disorder during pregnancy.

• The following results emerged from the collected data of a longitudinal, prospective cohort design that incorporated dual methods, hence a mixed research approach. Our findings are delineated under the following heads: socioeconomic and demographic profiles, clinical manifestation plus complications during pregnancy, access to health care and management of the disease, neonatal health outcomes and awareness and education on SCA.

• These outcomes mirror not only local conditions in Shahdol district but also wider trends noticed among SCA research in India, particularly in regions with substantial tribal populations. By bringing up these findings, we intend to contribute to the growing literature on SCA during pregnancy and emphasize areas that need immediate consideration by healthcare providers, policymakers, and research.

It appears that creating awareness at the community level requires the development of healthcare infrastructure that includes maternal health services, so that the consideration of significantly improving MCH in India can be truly holistic. Elaborating on the detailed results, it is quite clear that SCA in pregnancy will have to be taken up with respect to socioeconomic status, conditional access to relevant healthcare, and strategies for the improvement of how diseases can be managed, beside community awareness on a large scale. The following sections now attempt to detail each aspect of our findings in order to give a nuanced understanding of both the challenge and the potential interventions for the management of SCA during pregnancy in this region of high prevalence in India.

Interpretation of Results-

1. Socio-economic and Demographic Profile: Our study revealed a concentration of sickle cell anemia (SCA) among socio-economically deprived women, with 80% below the poverty line. This accords with a bulk of the literature emanating from several studies, especially studies from India. For instance, Saxena et al. (2017) have noted for tribal groups in Gujarat that the incidence of SCD is high, and any interventions, therefore, must be customized for them. The way in which there was exaggeration among Scheduled Tribes (48%) in our study indicates both genetic and environmental influences on those groups.

2. Clinical Manifestations and Complications in Pregnancy: Conclusively, in our study, the fact that 56% of the severe anaemia and 65% of the other complications were prevalent in women with SCA testifies that they are exposed to a high health risk in the course of their pregnancy. This agrees with Jain et al., 2019, mentioning that Britain diagnoses and appropriately treats anaemia in pregnancy, so increasing the risks for both mothers and foetuses. The non-reporting of Vaso-occlusive cirs in our study is at variance with classical SCA presentation that needs to be further probed into. But the 20% rate of spontaneous miscarriage fits well with the more significant reproductive hazards of SC thought, commented on by Balgir (2019) in Madhya Pradesh.

3. Access for Health Care and Management of the Disease: In our study Health facilities were assessed to be available but very poor levels of quality and most importantly, limited specialization was found. It is also the echo of concerns raised by Italia et al., in the year 2015, which pointed out the impossibility of achieving adequate follow-up care in a resource-poor setting. Most concerning, though, is the complete absence of using SCA-specific medications among our participants, which echoes the urgent call for better management strategies by Desai et al. in 2017 from their research in tribal communities of Gujarat.

4. Neonatal Health Outcomes: A low-birth-weight rate of 20% and complication rate of 30% that we found with our sample is quite substantial and parallels other researchers in original studies. Smith et al. (1996) found an increased risk for small for gestational age among women with the SS

genotype. These point to the intergenerational effect of SCA and the much needed specialized neonatal care, which has been stressed by Upadhye et al. (2016) in their study about SCD infant cohorts in central India.

5. SCA Awareness and Education: Our study identified a critical need for enhancing awareness and education programs regarding SCA within the community. This is in line with a contention in many of the above-cited studies such as that of Olney, 1999, on public health strategies like genetic counselling. The important role of healthcare professionals during an SCA diagnosis and spreading of information cites our research, and that of Colah et al., 2018, about newborn screening in India.

Strength and Limitations of the study: This study on pregnant women with Sickle Cell Anaemia in Shahdol District of Madhya Pradesh has some main strengths, including a focused, comprehensive data collection process in the use of a mixed methodology followed by contextual relevance to areas of high prevalence of SCA in India. The existing literature aligns well with the identification of critical gaps in care, keeping in mind the socioeconomic factors and bringing out the health disparities of any marginalized community in a geographical area, informing possible policy decisions. However, there are some issues that even diminish the generalizability and depth of the analysis of this study. These include: small sample size of 25 participants, possibility of selection bias, lack of control group, self-reported data, inability to give generalized findings, inability to help determine causality, and obviate provision of objective health measurements, namely, a prospective cohort study rather than a cross-sectional study. These factors reduce the generalisability of findings, the enabling of establishing causal connections, and the provision of objective health measures. These strengths and weaknesses need to be balanced when interpreting the findings and planning for the future in this area.

CHAPTER: 6 CONCLUSION

The survey of 25 women diagnosed with sickle cell anaemia provides important information regarding the problems faced by these people in the country of India. Of note is the fact that the participants were predominantly from Gohparu and Jaisinghnagar: they were diverse, predominantly belonging to Scheduled Tribes and economically weak categories. The importance of targeting interventions aimed at sub-groups within these populations magnifies from this demographic profile.

The tone of concern was given by the medical history of these women: half of the respondents were carriers, a small percentage was documented with disease for sickle cell activity, and over one third did not know the type of genotype, and hence these represent real gaps in genetic counseling and education. Similarly, pregnancy outcomes were also poor, with high rates of complications such as severe anemia, acute chest syndrome, and significant rates of miscarriages. There is, by extension, an urge for promotion towards specialized care and support for the pregnant women already diagnosed with sickle cell anaemia.

Access to and awareness about healthcare were quite varied. While many women accessed regular healthcare services with ease, the quality of care and specificity was low. On the other hand, prenatal counselling or any form of important nutritional advice during pregnancy was not received by an overwhelming majority of the participants. There were no women who were put on any specific medications against sickle cell anaemia, indicating a possibly large flaw in treatment protocols or large-scale unavailability of medications.

These findings evidently reveal a significant incidence of health complications in neonates born of sickle cell anaemia mothers. However, without a control group of mothers without the disease, it is not possible to definitely conclude whether this is significantly greater than in the general population. The positive findings regarding sickle cell anaemia in pregnancy are that the observed complications, preterm birth and low birth weight, are consistent with the known risks of this condition. Many of the mothers, 56%, also had severe anaemia and other complications related to a pregnancy that could be responsible for the neonatal health issues that were observed.

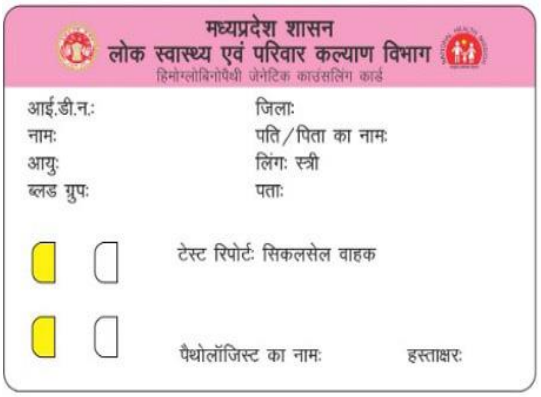
These results, therefore, are suggestive of an increased risk for neonatal complications in mothers with sickle cell anaemia; however, the small sample size and the absence of a control group limit the possibility to derive definitive conclusions or to perform statistical comparisons. This would demand doing more work with a larger sample, and include a relevant control group of mothers who did not have to cope with sickle cell anaemia in this sample, in order to test the hypothesis more rigorously, and be able to show whether the difference in neonate health complications is really significant in both the cases.

This, combined with a great lack of understanding of local interventions and the total absence of genetic counselling, underlines the demand for wide and comprehensive education and support programs.

Such recommendations are what form the following to face the problems.

• Emergency breaking of silence on the issue of sickle cell anaemia. Community voices must break the silence and de-stigmatize the condition by community education programs that should have far-reaching implications in stopping any myths, stigmatization, and prejudice associated with sickle cell anaemia and bring understanding by open dialogue about the condition in question.

• The role of genetic counselling cannot be overemphasized. Instituting and encouraging genetic counselling services in all centres managing sickle cell anaemia would be much fruitful. This shall inform the individuals on their genetic status, enable them to make informed choices for family planning and avail them of key that information on effective management of their condition.



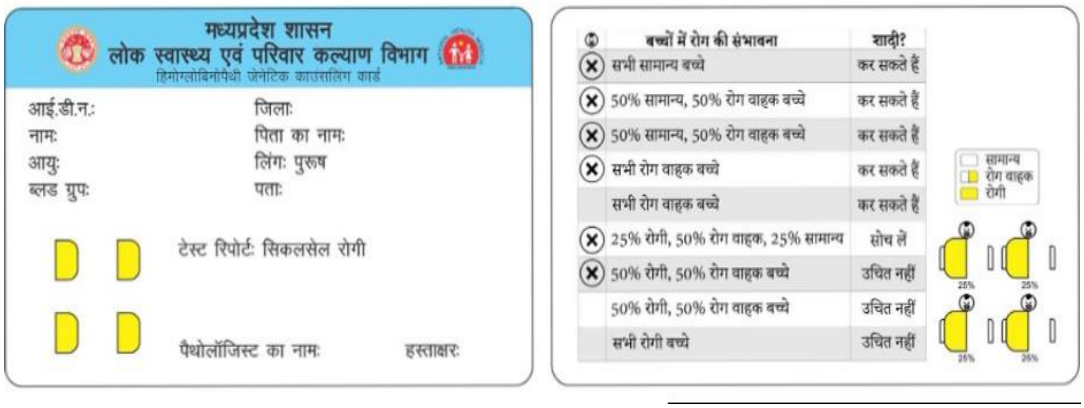


Fig 6.1: Genetic Counselling Cards to be used to counsel on the inheritance of Sickle Cell-related and other abnormal haemoglobin variants defective genes by children

- The National Sickle Cell Anaemia Elimination Mission, launched by the Prime Minister in July 2023, provides an appropriate and right opportunity to address all these issues at the national scale. This kind of program could be exploited by including components that have to do with new knowledge awareness creations like mass media campaigns and community outreaches. This system will further be applicable to enhancing the healthcare infrastructure of specialized care for patients with sickle cell anaemia, the availability of medications and treatments in all healthcare facilities. The other vital issue is the training of healthcare providers and community health workers regarding the management of sickle cell anaemia.
- Due to the high prevalence of pregnancy complications observed in the study, improved prenatal care is due for women with sickle cell anaemia. Comprehensive guidelines need to be developed to manage such high-risk pregnancies through regular monitoring, nutritional counselling, and early intervention for its complications.
- Sickle cell anaemia subjects many patients to unfavourable economic challenges. The integration of financial support mechanisms in the Sickle Cell Abhiyan will come to alleviate the burden, such as subsidies for medicine, treatment, and nutrition supplements.

Of course, such a small-scale study is instructive, but it emphasizes the need for a more wide-ranging research project. National-level studies will provide the exact scenario of prevalence, challenges, and needs of sickle cell anaemia patients in various regions and communities, and such information would be very crucial in developing relevant policy and effective interventions at the national level.

If India follows these recommendations, it could help in improving the quality of life and health of sickle cell patients. Also, informed family planning and genetic counselling could be beneficial in reducing the prevalence of the condition in future generations in the country. This requires joint efforts between health professionals, policymakers, and the community and affected individuals, as the potential benefits of improved health and quality of life stand to reason with this expended effort.

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ANNEXURE

Survey Questionnaire

A] Demographic Information

1. Name:

2. Age:

3. Mob. No.

4. Address:

5. Marital Status:

- Single
- Married
- Widowed
- Divorced/Separated

6. Education Level:

- No formal education
- Primary education
- Secondary education
- Higher education

7. Occupation:

- Unemployed
- Farmer
- Daily wage laborer
- Government employee
- Private sector employee

- Other (please specify):

8. Socioeconomic Status:

- Low

- Middle

- High

B] Medical History

1. At what age were you diagnosed with SCA?

2. What is your sickle cell anemia genotype?

- HbSS

- HbSC

- Other (please specify):

3. Do you have a family history of SCA?

- Yes

- No

- Don't know

4. Have you had any previous pregnancies?

- Yes

- No

5. If yes, please specify the number of pregnancies:

6. Have you experienced any complications related to sickle cell anemia during your pregnancies? (Select all that apply)

-Vaso-occlusive crisis

- Acute chest syndrome

- Severe anemia

- Preeclampsia

- Other (please specify):

7. Any history of pregnancy-related complications you faced during pregnancies (e.g., miscarriage, stillbirth, preterm birth)?

- Yes (please specify):

- No

8. Have you been counseled or educated about the potential risks and complications associated with sickle cell anemia during pregnancy?

- Yes

- No

C] Health and Lifestyle

1. Do you take any medications for SCA?

- Yes (please specify):

- No

2. Did you receive any specific treatments for SCA during pregnancy (e.g., blood transfusions)?

- Yes (please specify):

- No

3. Have you been advised on nutrition and diet during pregnancy?

- Yes

- No

4. Do you have access to nutritional supplements (e.g., folic acid, iron)?

- Yes

- No

5. Do you experience any of the following symptoms frequently?

- Pain crises

- Fatigue

- Shortness of breath

- Swelling in hands/feet

- Other (please specify):

D] Neonatal Information

1. What was the birth weight of your baby? ___ grams

2. Was your baby born preterm?

- Yes

- No

3. Did your baby experience any health complications after birth?

- Yes (please specify): ___

- No

4. Did your baby require NICU (Neonatal Intensive Care Unit) admission?

- Yes

- No

E] Knowledge and Awareness

1. How did you learn about Sickle Cell Anemia?

- Family

- Healthcare provider

- Community health worker

- Media

- Other (please specify):

2. Are you aware of any interventions or programs for SCA in your area?

- Yes (please specify):

- No

3. Have you received any genetic counseling regarding SCA?

- Yes

- No

4. Do you think more awareness and educational programs are needed in your community regarding SCA?

- Yes

- No

F] Healthcare Access and Interventions

1. How far is the nearest healthcare facility from your home? ___ km

2. Do you have access to regular healthcare services for SCA management?

- Yes

- No

3. Are there any barriers to accessing healthcare services for you?

- Yes (please specify): ___

- No

4. What interventions or support would you like to see implemented to better manage SCA in pregnant women?

- Improved healthcare facilities
- More frequent antenatal visits
- Access to specialized care
- Nutritional support
- Genetic counselling
- Other (please specify): ___

5. Do you have a Sickle Cell Anaemia Card?

- Yes
-No

G] Additional Comments

1. Please provide any additional comments or suggestions regarding the management of Sickle Cell Anaemia in pregnant women and neonatal care in your community:

Thank you for participating in this survey. Your responses are valuable in improving the healthcare services for Sickle Cell Anaemia in Shahdol District.

Consent Form

Study Title: Sickle Cell Anaemia among Pregnant Women and its Complications among Neonates: A Cross-Sectional Study in Shahdol District, Madhya Pradesh

Introduction: You are invited to participate in a research study aimed at understanding the prevalence of sickle cell anaemia among pregnant women in Shahdol District, Madhya Pradesh, and its impact on neonatal health outcomes. This study will provide valuable insights to inform public health policies and improve maternal and child health services in the region. The survey will take approximately 25-30 minutes to complete. Participation in this study is entirely voluntary, and you may withdraw at any time without any negative consequences. Before you decide to participate, it is important that you understand the purpose, procedures, risks, and benefits of the study.

Purpose of the Study: The purpose of this study is to assess the prevalence of sickle cell anaemia among pregnant women in Shahdol District and examine the associated neonatal complications. The findings will contribute to the development of targeted healthcare strategies and interventions for the prevention, early detection, and management of sickle cell anaemia during pregnancy.

Procedures: If you agree to participate in this study, you will be asked to complete a survey questionnaire. The questionnaire will gather information about your demographic details, medical history, pregnancy-related information, access to healthcare services, and your knowledge and awareness about sickle cell anaemia and its implications during pregnancy.

Risks and Discomforts: There are minimal risks associated with participating in this study. However, some questions may be of a sensitive nature and may cause emotional discomfort. You have the right to skip any question that makes you uncomfortable or to withdraw from the study at any time without any penalty.

Benefits: There may be no direct benefits to you for participating in this study. However, the information you provide will help researchers better understand the impact of sickle cell anaemia on maternal and neonatal health outcomes in Shahdol District. This knowledge may contribute to the development of effective interventions and improved healthcare services for individuals affected by sickle cell anaemia.

Confidentiality: All information collected during this study will be kept strictly confidential. Your personal information will be coded, and no identifying information will be included in any report or publication resulting from this study. Only the research team will have access to the coded data.

Voluntary Participation: Your participation in this study is entirely voluntary. You have the right to refuse to participate or to withdraw from the study at any time without any consequences or penalty.

Consent Statement:

By signing this consent form, you acknowledge that you have read and understood the information provided, and you agree to participate in this study.

Participant's Name: _____

Participant's Signature: _____ Date: _____

Researcher's Name: _____

Researcher's Signature: _____ Date: _____

TABLES

Block Name	No. Of Participants
Beohari	3
Burhar	4
Gohparu	7
Jaisinghnagar	6
Sohagpur	5
Grand Total	25

Distribution of Various Respondents of each Block

Caste	No. Of Participants
OBC	5
SC	8
ST	12
Grand Total	25

Distribution of Caste

Ration Card	Blocks	No. of Participants
APL	Beohari	1
	Gohparu	2
	Sohagpur	2
APL Total		5
BPL	Beohari	2
	Burhar	4
	Gohparu	5
	Jaisinghnagar	6
	Sohagpur	3
BPL Total		20
Grand Total		25

Distribution of Ration Cards among various blocks

Education Level	No. of Participants
Higher	5
No formal education	1
Primary	4
Secondary	15
Grand Total	25

Distribution of Education Level

Genotype	No. of Participants
Don’t know	9
HbAS	13
HbSS	3
Grand Total	25

Distribution of Genotype

Previous Pregnancy	No. Of Pregnancy
No	9
Yes	16
Grand Total	25

Distribution of Previous Pregnancy

Severe Anaemia	No. of Participants
No	11
Yes	14
Grand Total	25

Distribution of Severe Anaemia

Acute Chest Syndrome	No. Of Participants
No	18
Yes	7
Grand Total	25

Distribution of Acute Chest Syndrome

Blood Transfusions	No. of Participants
No	22
Yes: 1 blood unit	1
Yes: 2blood units	2
Grand Total	25

Distribution of Blood Transfusions

Nutrition Counselling	No. of Participants
No	16
Yes	9
Grand Total	25

Distribution of Nutrition Counselling

Pain Crisis	No. of Participants
No	15
Yes	10
Grand Total	25

Distribution of Symptom: Pain Crisis

Fatigue	No. of Participants
No	5
Yes	20
Grand Total	25

Distribution of Symptom: Fatigue

Shortness of Breath	No. of Participants
No	14
Yes	11
Grand Total	25

Distribution of Symptom: Shortness of Breath

Swelling of hands/ feet	No. of Participants
No	20
Yes	5
Grand Total	25

Distribution of Symptom: Swelling of hands/ feet

Preterm Baby	No. of Participants
NA	6
No	16
Yes	3
Grand Total	25

Distribution of Preterm baby

Neonatal Complications	No. of Participants
NA	6
No	12
Yes	1
Yes: fever after 10 days	1
Yes: Low birth weight	1
Yes: Meconium Aspiration leading to Neonatal Sepsis	1
Yes: missing of digestive canal	1
Yes: Jaundice	2
Grand Total	25

Distribution of Neonatal Complications

NICU Admission	No. of Participants
NA	6
No	9
Yes	10
Grand Total	25

Distribution of NICU Admissions

Community Health Worker	No. of Participants
No	18
Yes	7
Grand Total	25

Distribution of Intervention by Community Health Worker

Awareness of Interventions/ programs	No. of Participants
No	23
Yes: Camp	2
Grand Total	25

Distribution of Awareness/ Programs in their Areas

Improved Healthcare Facilities	No. of Participants
No	3
Yes	22
Grand Total	25

Distribution of Intervention / Support of Improved Healthcare Facilities in their Areas

Access to specialised Care	No. of Participants
No	9
Yes	16
Grand Total	25

Distribution of Intervention/ Support of Access to Specialised Care

Nutritional Support	No. of Participants
No	14
Yes	11
Grand Total	25

Distribution of Intervention / Support of Nutritional Support

Genetic Counselling	No. of Participants
No	23
Yes	2
Grand Total	25

Distribution of Intervention/ Support of Genetic Counselling

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Frequently Asked Questions

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What does 'qualifying text' mean?

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