



SICKLE CELL DISEASE AND MATERNAL HEALTH IN TRIBAL POPULATIONS: A COMPREHENSIVE REVIEW

Epidemiology

Dr.K Narayanasamy*	Public Health PG Research Scholar, Department of Epidemiology, The Tamilnadu Dr.M.G.R Medical University, Guindy, Chennai, Tamilnadu, India. *Corresponding Author
Dr. Maria Catherine	PG Research Scholar, Department of Epidemiology and Biostatistics, SRM School of Public Health, SRM Institute of Science and Technology, Kattankulathur, Chengalpattu, Tamil Nadu, India-603203
Dr. S Kalpana	Department of Epidemiology, The Tamilnadu Dr.M.G.R Medical University, Guindy, Chennai, Tamilnadu, India-600032.
Dr. Jasmine S Sunder	Department of Epidemiology, The Tamilnadu Dr.M.G.R Medical University, Guindy, Chennai, Tamilnadu, India 600032
Dr.S Valarmathi	Department of Epidemiology, The Tamilnadu Dr.M.G.R Medical University, Guindy, Chennai, Tamilnadu, India 600032
Dr.G Srinivas	Department of Epidemiology, The Tamilnadu Dr.M.G.R Medical University, Guindy, Chennai, Tamilnadu, India 600032.

ABSTRACT

Introduction: Sickle Cell Disease (SCD) has significant impacts on maternal and perinatal health, particularly among tribal groups. In India, where SCD is common in various populations, the prevalence ranges from 0.6% to 35%, depending on the population and screening methods. SCD is particularly prevalent among tribal groups, with rates ranging by area, including Gujarat, Madhya Pradesh, Odisha, and Chhattisgarh. The purpose of this review is to estimate the occurrence of SCD among tribal groups, as well as its implications on maternal health, identify gaps in healthcare facilities, and evaluate current treatment efficacy. **Methodology:** A complete literature search was carried out using databases such as PubMed, Google Scholar, and Scopus. The key search terms were "Sickle Cell Disease," "Maternal Health," "Tribal Populations," and "Pregnancy Complications." The inclusion criteria were based on peer-reviewed articles and research published during the last 10-15 years. Data from sickle-cell surveys in India from 2010 to 2023 were combined with an older database to produce an updated geodatabase for analysis. **Results:** The frequency of SCD among tribal communities in India ranges from 1% to 40%, with considerable regional variation. Tribal tribes in Gujarat, for example, have a high prevalence, with an estimated 1-2 million carriers and approximately 80,000 people affected by SCD. The condition has a significant influence on maternal health, with increased risk of stillbirth, low birth weight, and premature birth. Despite some protective variables, such as increased fetal hemoglobin levels, thorough care remains necessary. **Discussion:** Geographic, cultural, and economic limitations make SCD a special struggle in tribal groups. Limited access to healthcare, low awareness, and traditional beliefs all impede efficient disease management. Interventions such as expanded screening programs, integrated maternal health care, and community-based health models are critical for addressing these issues. Strengthening healthcare infrastructure and performing additional research on maternal outcomes in these communities will be critical for designing targeted interventions and providing better care.

KEYWORDS

Sickle Cell Disease (SCD), Maternal Health, Tribal Populations, Pregnancy Complications, Public Awareness, Vaso-occlusive Crisis

INTRODUCTION:

Sickle Cell Disease (SCD) is a genetic blood disorder characterized by the production of Abnormal hemoglobin, sometimes known as hemoglobin S. This causes red blood cells to form a hard, sickle-like shape, resulting in a variety of issues. SCD is inherited in an autosomal recessive way, thus a kid must acquire two copies of the sickle cell gene (one from each parent) to develop the condition (1). Sickle cell disease (SCD) has a significant impact on maternal and perinatal health, particularly in tribal populations. Studies have revealed an increased risk of preeclampsia, stillbirth, premature delivery, and small-for-gestational-age children in pregnant women with SCD compared to those without (2). In India, where SCD is prevalent among tribal communities, research has revealed a range of 0.6%-35% prevalence, depending on the population studied and screening methods used (3) SCD affects over 330,000 babies worldwide each year, with India accounting for roughly 14.5% of these cases. In India, it is particularly widespread among tribal tribes, with estimates suggesting that around one in every 86 births among Scheduled Tribes (STs) result in SCD (4). The sickle gene's prevalence among tribal populations varies widely, with an individual rates ranging between 1% and 40% depending on the location (5,6). Prevalence among tribal populations: SCD is very prevalent in India's tribal regions, including Gujarat, Madhya Pradesh, Odisha, and Chhattisgarh. For example, it is believed that over 1-2 million tribal individuals in Gujarat alone carry the sickle cell trait, with approximately 80,000 suffering by SCD (1,6). Research show that compared to non-tribal communities, SCD patients typically have lesser symptoms. Higher fetal hemoglobin levels and a higher prevalence of α -thalassemia in these cultures are the reasons for the reduced severity (5,7). However, some people continue to endure

severe symptoms of the condition. Maternal Health Implications: SCD presents significant dangers during pregnancy. According to studies, women with SCD had a higher risk of problems such as stillbirths (9.9% for SCD deliveries compared to 4.2% for non-SCD deliveries), low birth weight (70.2% vs. 43.8%), and preterm births (45% vs. 17.3%) (6). Furthermore, maternal problems such as severe anemia and the requirement for blood transfusions are substantially more likely in people with SCD (6).

While comprehensive data may be less common in Tamil Nadu than in places like Gujarat or Madhya Pradesh, the tribal inhabitants of the state are probably similarly impacted by comparable patterns of prevalence and maternal health outcomes linked to SCD. The Indian government has launched many efforts to control and manage SCD in indigenous populations. The National Sickle Cell Anemia Elimination Mission seeks to screen about 70 million people for sickle cell diseases over a few years (8). Despite these efforts, access to healthcare treatments remains an issue, as does the need for community awareness campaigns to reduce stigma and enhance management measures for afflicted persons (6). However, fetal mortality remains a worry. Recent breakthroughs in healthcare, notably the use of hydroxyurea and improved prenatal screening, have increased life expectancy and reproductive choices for people with SCD (9). Nonetheless, standardized screening approaches and additional research into SCD prevalence in non-tribal communities are required to improve maternal and fetal health. In summary, while there is a large prevalence of sickle cell disease among tribal people in India, particularly Tamil Nadu, continued efforts are required to enhance maternal health outcomes and offer comprehensive care for affected individuals.

Objectives:

To review of evaluate the incidence of SCD and its effects on the health of mothers in indigenous communities. To determine the gaps in healthcare service and research, as well as to assess the efficacy of present therapies.

Methodology: Literary Search Strategy:

Databases such as PubMed, Google Scholar, and Scopus were utilized to collect relevant articles. Key search terms included "Sickle Cell Disease," "Maternal Health," "Tribal Populations," "Pregnancy Complications," and "Vaso-occlusive Crisis." The search was limited to articles published within the last 10-15 years, with an emphasis on peer-reviewed research articles that met the inclusion criteria.

Creating An Updated Geodatabase Of Surveys.

We did a literature search of sickle-cell surveys in India from 2010 to 2023, as well as surveys available only in the local literature, including those older than 2010.

Using the methodologies detailed in Supplementary Information S1, selected references were evaluated for their ability to add to the evidence base supporting our mapping analysis. Surveys with known or suspected selection bias in health status or SCD risk were excluded. In addition, we only considered surveys that reported sample size and, at the very least, the number of sickle-cell heterozygotes found. Finally, only surveys that could be georeferenced to at least the district level were included.

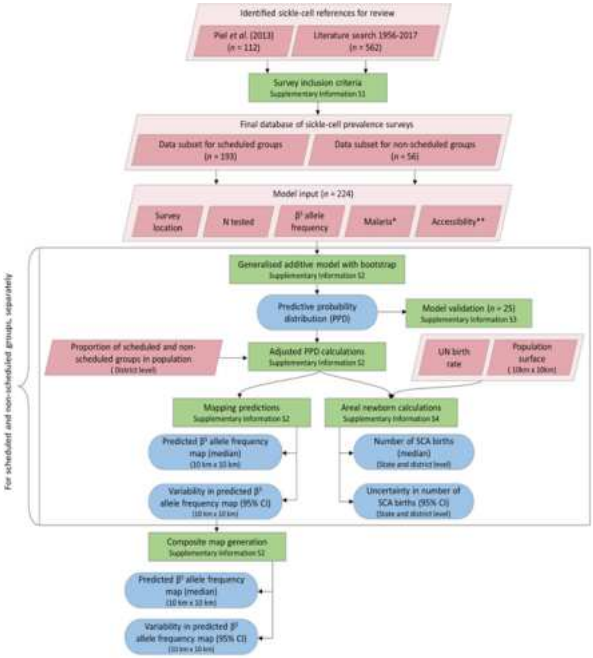


Figure 1(11)- A schematic representation of database production operations and geostatistical modeling processes. Pink diamonds indicate input data, green boxes denote methodological steps, and blue rods represent model output. *Maps of malaria endemicity throughout history and today. **Two urban accessibility metrics: evening lights and travel time to the nearest city (Supplementary Information).

Epidemiology Of Sickle Cell Disease In Tribal Populations: Prevalence And Distribution:

The prevalence of sickle cell carriers (heterozygotes) among tribal populations in India ranges between 1% and 40% (7,10). The distribution of sickle cell disease is concentrated in distinct "sickle cell belts" across central and western India, with 27 out of 45 districts in Madhya Pradesh falling inside it (7,11). In Gujarat, it is believed that 1-2 million the tribal population carry the sickle cell trait, with roughly 80,000 individuals suffering from sickle cell disease (7,11).

Impact Of Sickle Cell Disease On Maternal Health:

Investigate the specific challenges of pregnancy in women with SCD, such as Vaso-occlusive crises, an increased risk of miscarriage, pre-eclampsia, and maternal death. Discuss the effects on fetal outcomes such as preterm birth, low birth weight, and perinatal mortality. Sickle cell disease in tribal communities is typically milder than in non-tribal

groups due to a higher prevalence of α -thalassemia and raised fetal hemoglobin levels (8). However, some people still have significant symptoms of the condition, necessitating comprehensive care measures. According to studies, pregnant women with sickle cell disease have a higher chance of poor outcomes such stillbirths, low birth weight, and preterm deliveries (11,12).

Challenges And Interventions

Providing healthcare to indigenous populations has distinct problems, including restricted access to healthcare institutions and a lack of information regarding sickle cell disease within these communities (5,7). Some regions have launched outreach programs utilizing mobile clinics to improve access and provide regular monitoring for sickle cell disease patients (5,7). Educational programs are critical for decreasing stigma and increasing early detection and management of sickle cell disease in indigenous people (7). among conclusion, the epidemiology of sickle cell disease among tribal populations indicates important public health concerns that necessitate focused interventions and ongoing research to improve care and management measures.

Table 1.Healthcare Access And Barriers To Care:

Aspect	Sickle Cell Disease in Tribal Populations	Impact on Maternal Health
Geographic Barriers(4)	Remote areas with limited infrastructure and transportation.	Difficulty in accessing prenatal care, leading to higher maternal and fetal risks
Lack of Awareness (4,6)	Low awareness about SCD leads to delayed diagnosis and treatment.	Delayed diagnosis of SCD in pregnant women increases risk of complications during pregnancy
Financial Constraints (6)	High costs of managing SCD, including hospital visits and medications.	Economic burden on families can delay or prevent access to essential maternal care.
Quality of Care(6,7)	Inadequate healthcare services and limited access to specialized care	Suboptimal management of SCD during pregnancy increases the risk of adverse maternal outcomes.
Cultural Beliefs(6)	Traditional practices and reliance on alternative treatments	Hesitation to seek conventional medical care can result in poor maternal health outcomes

Psychosocial Impact:

Sickle Cell Disease (SCD) has a substantial psychosocial impact on tribal groups, including stigma and prejudice. Misconceptions regarding the condition can cause social isolation among affected individuals, resulting to mental health issues such as anxiety and sadness. The economic pressure of managing SCD adds to these concerns, as families face high medical expenditures and the prospect of losing income. This situation underscores the vital need for culturally suitable support systems and awareness campaigns to improve the quality of life for those affected with SCD in tribal groups, addressing both physiological and psychological factors effectively.

Future Directions And Recommendations:

Sickle Cell Disease (SCD) causes serious health problems, notably among tribal groups in India. The disease's prevalence and impact on maternal health in these communities call for specific interventions and future approaches in comprehensive care.

Enhanced Screening Programs:

The National Sickle Cell Elimination Mission intends to screen 7 crore people in tribal areas by 2026. This effort comprises awareness campaigns and universal screenings for people aged 0 to 40(13). Continued expansion and funding for these programs is critical to ensuring early detection and intervention.

Integrated Maternal Health Services:

The inclusion of SCD treatment in maternal health services is crucial. In order to identify carriers and affected persons early on, this involves prenatal screening and counseling for expectant mothers in tribal communities (14). Putting thorough maternity care procedures into

practice could greatly enhance the outcomes for moms and babies.

Community-Based Health Models:

Creating models for community-based healthcare can improve patient access. In isolated tribal areas, for instance, mobile health units and qualified local health professionals can offer routine monitoring and instruction in SCD management (7).

Strengthening Healthcare Infrastructure:

Tribal communities will have easier access to healthcare if Centers of Excellence for diagnosis and treatment are established across state lines. These facilities ought to prioritize teaching patients on SCD management techniques in addition to providing therapy (13).

Research On Maternal Outcomes:

Information on the prenatal and maternal outcomes for women with sickle cell disease (SCD) in indigenous communities is scarce. Future studies should concentrate on comprehending these results in order to create focused therapies that cater to these women's particular needs (7).

Genetic Counseling Services:

Offering genetic counseling in the community can assist families understand the implications of SCD and make educated reproductive decisions. This service should be integrated into the existing healthcare frameworks in tribal regions (14,15).

Public knowledge Campaigns:

Raising knowledge about SCD through community meetings, school programs, and local media can enable tribal populations to seek timely medical attention and support (14).

Implementing these recommendations can considerably enhance the management of sickle cell disease among tribal populations, eventually increasing maternal health outcomes and overall community well-being.

CONCLUSION

Sickle Cell Disease (SCD) is prevalent among tribal people in India, owing to genetic predisposition, limited access to healthcare, and inadequate maternal health services. Key risk factors include a lack of screening, insufficient healthcare infrastructure, and low awareness. To improve outcomes, comprehensive interventions such as better screening, integrated healthcare services, and targeted public health initiatives must be implemented.

DISCUSSION:

Sickle Cell Disease (SCD) poses substantial issues for tribal groups, notably maternal health. Geographic, cultural, and economic barriers prevent efficient illness management, increasing the risk of stillbirths, low birth weight, and premature deliveries among pregnant women. These challenges are exacerbated by limited access to healthcare, traditional beliefs, and a lack of information. In certain native groups, higher fetal hemoglobin levels provide some protection, although thorough care is still required. Addressing these issues through expanded screening, integrated maternal care, and community-based health models is critical to improving maternal and fetal outcomes in these underserved communities.

Ethical Considerations

Not applicable.

Funding Statement

No funding sources.

Disclosure Of Interest

The authors declare that they have no competing interest.

Informed Consent

Not applicable.

REFERENCES

- Desai G, Anand A, Shah P, Shah S, Dave K, Bhatt H, et al. Sickle cell disease and pregnancy outcomes: a study of the community-based hospital in a tribal block of Gujarat, India. *J Health Popul Nutr*. 2017 Jan 21;36:3.
- Oteng-Ntim E, Meeks D, Seed PT, Webster L, Howard J, Doyle P, et al. Adverse maternal and perinatal outcomes in pregnant women with sickle cell disease: systematic review and meta-analysis. *Blood*. 2015 May 21;125(21):3316–25.
- Saxena D, Yasobant S, Golechha M. Situational Analysis of Sickle Cell Disease in Gujarat, India. *Indian J Community Med Off Publ Indian Assoc Prev Soc Med*.

- 2017;42(4):218–21.
- Union Minister of Tribal Affairs, Shri Arjun Munda chairs Sensitization Workshop on Sickle Cell Disease on World Sickle Cell Day in the virtual mode [Internet]. [cited 2024 Sep 19]. Available from: [https://pib.gov.in/pib.gov.in/Press release share.aspx?PRID=1933456](https://pib.gov.in/pib.gov.in/Press%20release%20share.aspx?PRID=1933456)
- Colah RB, Mukherjee MB, Martin S, Ghosh K. Sickle cell disease in tribal populations in India. *Indian J Med Res*. 2015 May;141(5):509–15.
- Sickle cell disease in India: a scoping review from a health systems perspective to identify an agenda for research and action | *BMJ Global Health* [Internet]. [cited 2024 Sep 19]. Available from: <https://gh.bmj.com/content/6/2/e004322>
- Sickle cell disease in tribal populations in India - PMC [Internet]. [cited 2024 Sep 19]. Available from: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4510747/>
- National Sickle Cell Anaemia Elimination Mission [Internet]. [cited 2024 Sep 19]. Available from: <https://sickle.nhm.gov.in/home/about>
- Sickle cell anemia/sickle cell disease and pregnancy outcomes among ethnic tribes in India: an integrative mini-review: *The Journal of Maternal-Fetal & Neonatal Medicine*: Vol 35 , No 25 - Get Access [Internet]. [cited 2024 Sep 19]. Available from: <https://www.tandfonline.com/doi/full/10.1080/14767058.2021.1872536>
- The spatial epidemiology of sickle-cell anaemia in India | *Scientific Reports* [Internet]. [cited 2024 Sep 20]. Available from: <https://www.nature.com/articles/s41598-018-36077-w>
- Burden of sickle cell disease in tribal students in Maa-Baadi institutions in southern Rajasthan - A pilot study - PMC [Internet]. [cited 2024 Sep 19]. Available from: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC10057375/>
- Rao P, Raj EA, Natesan S, Gudi N. Prevalence of Sickle cell disease, Sickle cell trait and HBS-beta-thalassemia in India: A systematic review and Meta-analysis. *Clin Epidemiol Glob Health* [Internet]. 2024 Jul 1 [cited 2024 Sep 19];28. Available from: <https://cegh.net/article/S2213-3984%2824%2900174-X/fulltext>
- 7 crore people in tribal areas to be screened for sickle cell disease by 2025-26: FM - *The Hindu* [Internet]. [cited 2024 Sep 20]. Available from: <https://www.thehindu.com/sci-tech/health/7-crore-people-in-tribal-areas-to-be-screened-for-sickle-cell-disease-by-2025-26-fm/article66459688.ece>
- National Sickle Cell Disease Control Programme [Internet]. [cited 2024 Sep 20]. Available from: <https://sickle.nhm.gov.in/sickle2.0/home/about>
- Ministry of Tribal Affairs - Government of India [Internet]. [cited 2024 Sep 20]. Available from: <https://tribal.nic.in/sickle-cell-disease-piramal-swasthya.aspx>