International Journal for Research Trends in Social Science & Humanities
Volume 4, Issue 3
May-June- 2026, PP 1-8

"Determinants of Sickle Cell Disease Outcomes in Tribal India: A Mixed-Methods Study from Chhattisgarh"

Dr. Shahla Khan[1], Dr. P.K. Patra[2].
[1]Senior Project Associate, CRISPR Clinical Trials Project, Pt. Deendayal Upadhyaya Memorial Health Sciences and AYUSH University of Chhatisgarh , India
[2]Vice Chancellor, Pt. Deendayal Upadhyaya Memorial Health Sciences and AYUSH University of Chhatisgarh , India
Corresponding author: Shahla Khan
Email: shahlak781@gmail.com

Abstract- Sickle Cell Disease (SCD) is a hereditary hemoglobin disorder with a high prevalence among tribal populations in central India, particularly in the Bastar region of Chhattisgarh. The socio-economic status (SES) of individuals affected by SCD is generally low, with a disproportionate burden among Scheduled Tribes (ST), Scheduled Castes (SC), and Other Backward Classes (OBC), who predominantly reside in remote areas with limited access to healthcare services. This study examines the socio-economic and psychosocial challenges faced by SCD patients in tribal areas of Bastar, focusing on healthcare access, education, employment, and social stigma. A mixed-methods approach was employed, incorporating field surveys, semi-structured interviews, and secondary data analysis. The findings reveal substantial barriers to healthcare access, low educational attainment, economic vulnerability, and widespread social stigma, all of which significantly impact quality of life. The study highlights the urgent need for targeted, culturally sensitive interventions to improve healthcare delivery, enhance socio-economic conditions, and reduce stigma associated with SCD in tribal regions.

Keywords: Sickle Cell Disease, Socioeconomic Status, Tribal Communities, Bastar, Healthcare Access, Social Stigma.

I. Introduction

Sickle Cell Disease (SCD) is a major hereditary hemoglobinopathy and a significant public health concern in India, particularly among tribal and socio-economically marginalized populations in central and eastern regions. States such as Chhattisgarh, Madhya Pradesh, Maharashtra, Odisha, and Gujarat report a high prevalence of the sickle cell gene, largely due to historical endogamy and limited population mobility.

Among these regions, Chhattisgarh—especially the Bastar region—represents a critical hotspot due to its dense tribal population and persistent structural disadvantages. SCD disproportionately affects marginalized communities, including Scheduled Tribes (ST), Scheduled Castes (SC), and Other Backward Classes (OBC), who often experience chronic poverty, low educational attainment, and limited access to healthcare services.

The disease significantly reduces quality of life through recurrent morbidity, frequent hospitalizations, and long-term dependency, thereby reinforcing cycles of socio-economic vulnerability. Tribal communities in Bastar, including the Gond, Muria, Hill Maria, Bhatara, Dhurva, and Halba groups, exhibit high frequencies of the sickle cell trait, ranging from 15% to 25% in certain populations.

Despite government initiatives, healthcare access remains limited due to geographic isolation, poor infrastructure, and inadequate diagnostic facilities. Socio-economic deprivation further exacerbates disease burden, as many households depend on subsistence agriculture or daily wage labor, with limited capacity to afford treatment.

In addition, low literacy levels restrict awareness regarding the genetic nature of SCD and preventive strategies. Cultural beliefs and stigma further complicate disease management, with misconceptions often leading to discrimination, delayed treatment, and reliance on traditional healing practices.
Given this context, the present study investigates the socio-economic and psychosocial dimensions of SCD in Bastar using a mixed-methods approach, aiming to generate context-specific insights to inform policy and healthcare interventions.

II. Literature Review

2.1 Prevalence of SCD in Tribal Populations

SCD is widely prevalent across central and western India, particularly among tribal populations. The frequency of the sickle cell trait varies significantly, ranging from 1% to 40% depending on the region and community. In Chhattisgarh, tribal groups such as Gond, Halba, and Muria exhibit particularly high prevalence rates.

2.2 Socio-Economic Determinants

Existing literature consistently highlights that SCD disproportionately affects economically disadvantaged populations. Most affected households live below the poverty line, limiting access to healthcare services and long-term treatment. Economic vulnerability contributes to delayed care-seeking and increased disease complications.

2.3 Educational Attainment

Low literacy and limited health awareness are major challenges in tribal regions. Children with SCD frequently experience school absenteeism due to illness, resulting in poor academic performance and high dropout rates. This further perpetuates cycles of poverty and disease burden.

2.4 Healthcare Access

Geographic isolation, lack of trained personnel, and inadequate diagnostic facilities significantly hinder effective disease management. In many cases, SCD symptoms are misdiagnosed due to the absence of confirmatory tests.

2.5 Cultural Beliefs and Stigma

Cultural misconceptions regarding SCD often result in stigma and discrimination. Beliefs linking the disease to supernatural causes or contagion negatively influence healthcare-seeking behavior and social participation.

2.6 Research Gaps

Despite extensive research, localized studies focusing on socio-economic and psychosocial aspects in regions like Bastar remain limited. This study addresses this gap by providing a context-specific analysis.

III. Methodology

This study employed a mixed-methods research design to examine the socio-economic conditions associated with SCD in the tribal areas of Bastar, Chhattisgarh.

Figure 1. Conceptual Framework of Study Design

Population Selection → Quantitative Survey (n=150) → Qualitative Interviews (n=20) → Data Analysis → Triangulation → Findings

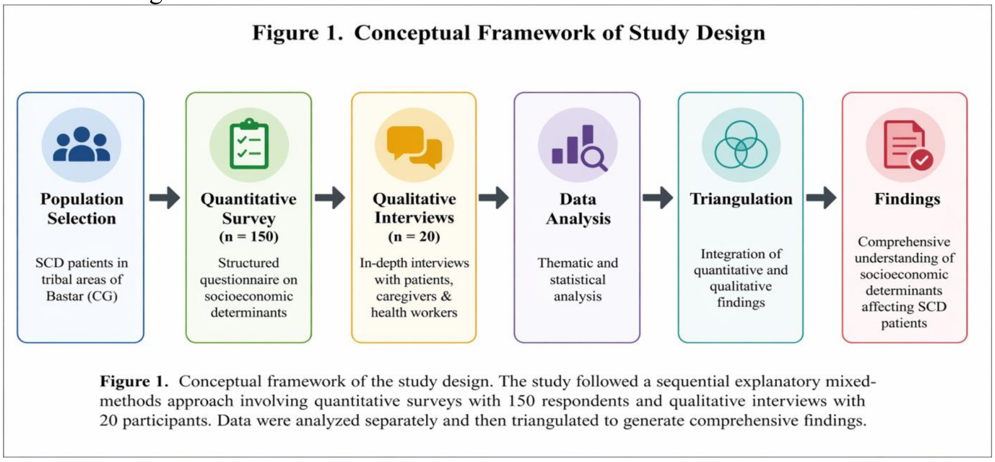

Figure 1. Conceptual Framework of Study Design

Figure 1. Conceptual framework of the study design. The study followed a sequential explanatory mixed-methods approach involving quantitative surveys with 150 respondents and qualitative interviews with 20 participants. Data were analyzed separately and then triangulated to generate comprehensive findings.

3.1 Study Area and Population

The study was conducted in selected tribal villages characterized by geographic isolation and limited infrastructure. The population included individuals diagnosed with SCD (HbSS) and carriers (HbAS).

3.2 Research Design

A combination of quantitative and qualitative methods was used to ensure comprehensive analysis.

3.3 Quantitative Component

- Sample size: 150 respondents
- Sampling: purposive and snowball techniques
- Tool: structured questionnaire
- Domains:
    - Demographics
    - Socio-economic status
    - Healthcare access
    - Education
    - Stigma

3.4 Qualitative Component

Twenty semi-structured interviews were conducted to explore lived experiences, cultural beliefs, and coping mechanisms.

3.5 Data Sources

Secondary data were collected from government reports, census data, and peer-reviewed literature.

3.6 Data Analysis

- Quantitative: descriptive statistics
- Qualitative: thematic analysis
- Triangulation was used to enhance validity and reliability

IV. Results

4.1 Healthcare Access

Only 24.06% of respondents reported having satisfactory access to healthcare services, while 75.94% experienced limited or no access. Geographic isolation, financial constraints, and lack of infrastructure were key barriers.

Figure 2. Access to Healthcare Services among SCD Patients

Category	Percentage (%)
Satisfactory Access	24.06
Limited / No Access	75.94

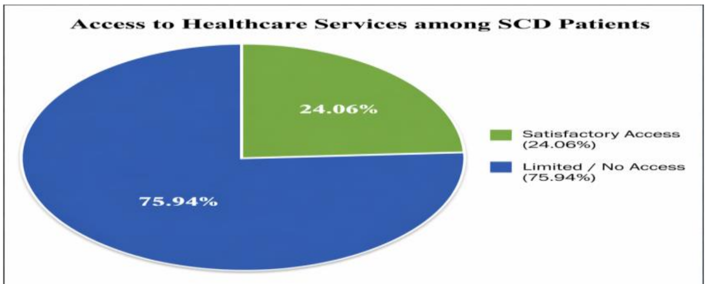

Figure 2. Distribution of access to healthcare services among sickle cell disease patients in the tribal areas of Bastar, Chhattisgarh. A majority (75.94%) reported limited or no access, highlighting significant healthcare gaps.

4.2 Educational Attainment

Nearly 48.5% of respondents had no formal education. Frequent illness and hospital visits contributed to school absenteeism and dropout.

Figure 4. Educational Status of Respondents

Education Level	Percentage (%)
No Formal Education	48.5
Primary	25
Secondary	18
Higher Education	8.5

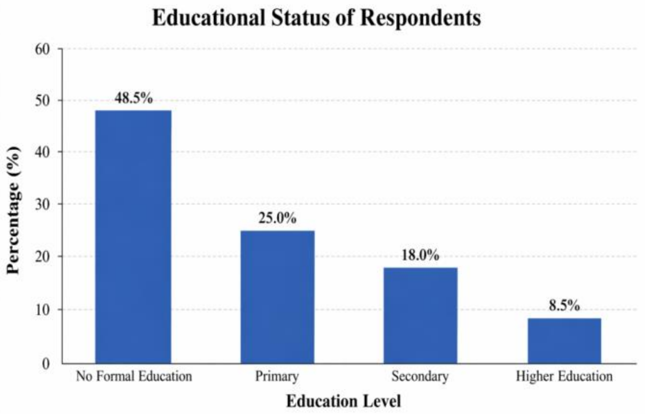

Figure 4. Distribution of educational status among respondents in the tribal areas of Bastar, Chhattisgarh. Nearly half (48.5%) of the respondents had no formal education, indicating low literacy levels in the community.

4.3 Employment and Economic Impact

Most respondents were engaged in low-income occupations such as agriculture and daily wage labor. SCD-related limitations reduced productivity and income stability. Healthcare expenses accounted for approximately 14–15% of annual household income.

Figure 5. Economic Burden of SCD

Indicator	Value (%)
Healthcare Expenditure	15
Income Loss	30
Financial Dependency	65

Employment Status and Economic Impact

Most respondents were engaged in low-paying occupations. Healthcare expenditure accounted for approximately 14–15% of annual household income.

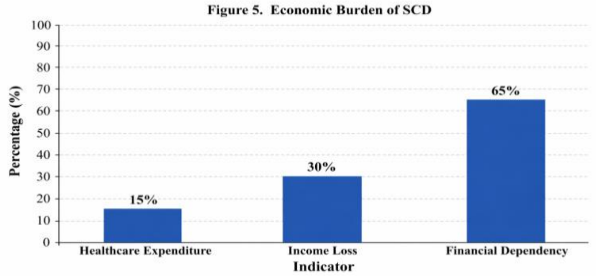

Figure 5. Economic burden of sickle cell disease (SCD) on affected households in the tribal areas of Bastar, Chhattisgarh. Financial dependency (65%) and income loss (30%) represent the major economic challenges.

4.4 Social Stigma and Psychosocial Impact

A significant proportion of respondents reported experiencing stigma:

- 46% high stigma
- 34% moderate stigma
- 20% low/no stigma
- **Figure 3. Social Stigma Distribution**

Stigma Level	Percentage (%)
High	46
Moderate	34
Low / None	20

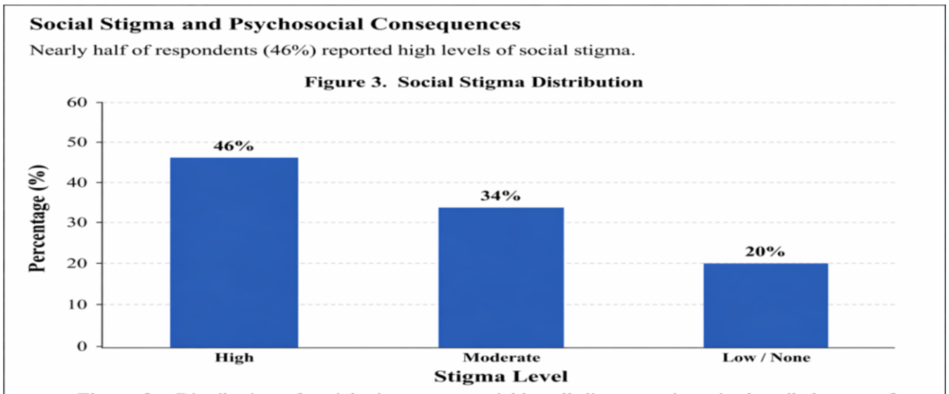

Figure 3. Distribution of social stigma among sickle cell disease patients in the tribal areas of Bastar, Chhattisgarh. Nearly half of respondents (46%) experienced high levels of stigma, indicating significant psychosocial burden.

Figure 6. Key Determinants Affecting SCD Patients

Factor	Impact (%)
Healthcare Access	76
Low Education	49
Economic Burden	65
Social Stigma	80

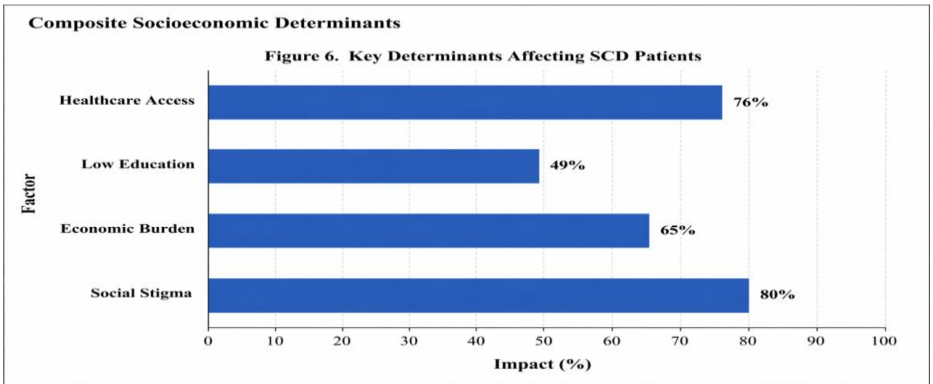

Figure 6. Key socioeconomic and psychosocial determinants affecting sickle cell disease (SCD) patients in the tribal areas of Bastar, Chhattisgarh. Social stigma (80%) and healthcare access (76%) emerged as the most significant challenges, followed by economic burden (65%) and low education (49%).

Stigma negatively affected marriage prospects, employment opportunities, and social participation, contributing to psychological distress and social isolation.

V. Discussion

The present study highlights that Sickle Cell Disease (SCD) in the Bastar region of Chhattisgarh extends far beyond a biomedical condition and is deeply embedded within a complex interplay of socioeconomic and psychosocial determinants. The mixed-methods findings underscore that limited access to healthcare services, low literacy levels, economic hardship, and entrenched cultural beliefs collectively shape disease experiences and outcomes among tribal populations.

Consistent with the quantitative findings, a substantial proportion of participants reported inadequate access to healthcare facilities, with distance, transportation challenges, and limited availability of specialized services acting as major barriers. These structural constraints contribute to delayed diagnosis, irregular follow-up, and poor adherence to treatment regimens. Similar observations have been reported in other tribal and resource-limited settings, where geographic isolation significantly impacts chronic disease management.

Educational status emerged as a critical determinant influencing disease awareness and health-seeking behavior. Low literacy levels were associated with poor understanding of disease etiology, preventive strategies, and treatment adherence. This gap in knowledge reinforces misconceptions and perpetuates reliance on informal or traditional systems of care.

The study also revealed a high psychosocial burden, particularly in the form of stigma and social exclusion. Participants frequently reported discrimination, reduced marriage prospects, and social isolation, which negatively affected mental well-being and healthcare utilization. Such findings align with existing literature emphasizing the hidden psychosocial dimensions of SCD, especially in marginalized communities.

Economic vulnerability further compounds these challenges. The majority of affected households belonged to low-income groups, and the cost of transportation, medications, and repeated hospital visits imposed a significant financial burden. This often resulted in delayed care-seeking or discontinuation of treatment, thereby exacerbating disease complications.

Qualitative insights provided deeper context to these findings, revealing a strong dependence on traditional healing practices. While these practices are culturally rooted and socially accepted, their use—often as the first line of treatment—can delay timely medical intervention. This reflects not only cultural beliefs but also systemic gaps in accessible and culturally sensitive healthcare delivery.

The integration of quantitative and qualitative data in this study strengthens the evidence that addressing SCD in tribal regions requires a multidimensional approach. Interventions must go beyond clinical management to include community-based awareness programs, culturally appropriate health education, strengthening of primary healthcare infrastructure, and financial protection mechanisms.

Overall, the findings emphasize that effective management of SCD in Bastar necessitates addressing the broader social determinants of health. Policies targeting healthcare accessibility, education, and socioeconomic upliftment are essential to reduce disease burden and improve quality of life among tribal populations.

Social stigma remains a major barrier, affecting mental health and healthcare-seeking behavior. These findings are consistent with studies conducted in other tribal regions of India, highlighting systemic inequalities.

VI. Conclusion and Future Directions

SCD continues to represent a significant public health challenge in the Bastar region, disproportionately affecting already vulnerable tribal populations. The burden of the disease extends beyond biological factors, encompassing socio-economic deprivation, limited healthcare access, and social stigma.

Improving outcomes requires:

- Strengthening healthcare infrastructure
- Expanding diagnostic and screening services
- Promoting community-based awareness programs
- Enhancing livelihood opportunities
- Addressing stigma through culturally sensitive interventions

Future research should focus on longitudinal studies, economic burden analysis, and evaluation of community-based healthcare models.

VII. Acknowledgements

The authors sincerely acknowledge the Department of Science and Technology (DST), Government of India, for financial support. Gratitude is extended to all contributors, institutions, and participants who supported this research.

VIII. Funding

This study was supported by the Department of Science and Technology (DST), Government of India.

IX. Conflict of Interest

The authors declare no conflict of interest.

X. Ethical Approval

Not applicable.

References

1. Balgir RS. The burden of hemoglobinopathies in India and the challenges ahead. Curr Sci. 2005;88(6):915–918.
2. Balgir RS. Genetic epidemiology of sickle cell disease in India. J Indian Anthropol Soc. 2010;45:1–14.
3. Bartolucci P, Galactéros F. Clinical management of adult sickle-cell disease. Curr Opin Hematol. 2012;19(3):149–155. doi:10.1097/MOH.0b013e328351c35f
4. Bhagat V, Baviskar S, Mudey A, Goyal R. Poor health-related quality of life among patients with sickle cell disease. Indian J Palliat Care. 2014;20(2):107–111. doi:10.4103/0973-1075.132622
5. Bhat D. Stigma and psychosocial challenges in sickle cell disease among Indian tribal populations. J Public Health. 2023.
6. Chauhan P. Maternal mortality among tribal women at a tertiary level of care in Bastar, Chhattisgarh. J Health Popul Dev Ctries. 2012;15(1):1–6.
7. Colah RB, Mukherjee MB, Martin S, Ghosh K. Sickle cell disease in tribal populations in India. Indian J Med Res. 2015;141(5):509–515.
8. Gupta RB. Sickle cell disease in central India: Need for micro-level studies. NIRTH Bull. 2008;13(1–2):1–4.
9. Hockham C, Bhatt S, Colah R, et al. The spatial epidemiology of sickle-cell anaemia in India. Sci Rep. 2018;8:17685. doi:10.1038/s41598-018-36077-w
10. Holdford D, Vendetti N, Sop DM, Johnson S, Smith WR. Indirect economic burden of sickle cell disease. Value Health. 2021;24(8):1095–1101. doi:10.1016/j.jval.2021.02.014
11. Inusa BPD, Hsu LL, Kohli N, et al. Sickle cell disease—genetics, pathophysiology, clinical presentation and treatment. Int J Neonatal Screen. 2019;5(2):20. doi:10.3390/ijns5020020
12. Jain D, Italia K, Sarathi V, Colah RB. Sickle cell disease in tribal populations of India: A systematic review. Indian J Med Res. 2012;136(3):403–412.
13. Kshirsagar AY, Patil S, Patil P, Patil N. Socioeconomic impact of sickle cell disease on families in India. J Family Med Prim Care. 2016;5(2):396–399.
14. Kumar MM, Pathak VK, Ruikar M. Tribal population in India: A public health challenge and road to future. J Family Med Prim Care. 2020;9(2):508–512. doi:10.4103/jfmpc.jfmpc_992_19
15. Leeflang MMG, Bossuyt PMM, Irwig L. Diagnostic test accuracy may vary with prevalence: implications for evidence-based diagnosis. J Clin Epidemiol. 2009;62(1):5–12.
16. Ministry of Tribal Affairs, Government of India. National sickle cell anaemia elimination mission [Internet]. 2016 [cited 2026 Apr 24]. Available from: https://sickle.nhm.gov.in
17. Ministry of Tribal Affairs, Government of India. Tribal health action plan. 2021.
18. Mohanty D, Colah RB, Gorakshakar A, Patel R. Burden of sickle cell disease in tribal communities of India. Indian Pediatr. 2014;51:101–105.
19. National Health Mission. Guidelines for prevention and control of hemoglobinopathies in India. New Delhi: Ministry of Health & Family Welfare; 2019.
20. National Institute for Research in Tribal Health. Tribal health bulletin. Jabalpur: NIRTH; 2007.
21. National Institute for Research in Tribal Health. Sickle cell disease control programme in Chhattisgarh. Jabalpur: NIRTH; 2018.

22. Niranjan R, Sahu P, Patel M. Awareness and perception of sickle cell disease among tribal populations. J Genet Couns. 2010;19(3):291–298.
23. Piel FB, Patil AP, Howes RE, et al. Global epidemiology of sickle haemoglobin in neonates. Lancet. 2013;381(9861):142–151.
24. Raman V, Seshadri T, Joice SV, Srinivas PN. Sickle cell disease in India: a scoping review from a health systems perspective. BMJ Glob Health. 2021;6(2):e004322. doi:10.1136/bmjgh-2020-004322
25. Rao S, Subhashini J, Reddy BM. Quality of life among patients with sickle cell disease in India. Indian J Hematol Blood Transfus. 2018;34(3):455–461.
26. Sareen N, Gupta S, Singh A. Socioeconomic burden of sickle cell disease in tribal regions of India. J Community Health. 2019;44(2):367–374.
27. Shrivastava PK, Bansal AK, Kantharaj CS. Incidence of sickle cell disorder among tribal and non-tribal communities of Bastar, India. Res J Sci Technol. 2009;1(1):33–34.
28. Singh P, Deorari AK. Challenges in implementation of sickle cell disease screening programs in India. Indian Pediatr. 2018;55(8):669–672.
29. Sickle cell disease among Gond tribe in Chhattisgarh. Int J Rev Res Soc Sci. 2025.
30. Sundd P, Gladwin MT, Novelli EM. Pathophysiology of sickle cell disease. Annu Rev Pathol. 2019;14:263–292.
31. Surve RR, Mukherjee MB, Kate SL, et al. Detection of the beta-S gene: evaluation of solubility test against chromatography and electrophoresis. Br J Biomed Sci. 2000;57(4):292–294.
32. Thakur A, Sharma R, Verma S. Barriers to healthcare access among tribal populations in central India. J Public Health Policy. 2017;38(4):513–528.
33. Thomson AM, McHugh TA, Oron AP, et al. Global prevalence and mortality burden of sickle cell disease, 2000–2021. Lancet Haematol. 2023.
34. Weatherall DJ, Clegg JB. Inherited haemoglobin disorders: an increasing global health problem. Bull World Health Organ. 2001;79(8):704–712.
35. World Bank. Poverty and health in tribal regions of India. Washington (DC): World Bank Publications; 2018.
36. World Health Organization. Framework on integrated, people-centred health services. Geneva: WHO; 2016.