INTERNATIONAL JOURNAL OF
PHARMACEUTICAL AND HEALTHCARE INNOVATION
journal homepage: www.ijphi.com

Research Article

Beyond Biology: Socioeconomic and Psychosocial Dimensions of Sickle Cell Disease in Tribal Communities of Chhattisgarh, India

Dr. Shahla Khan*[1], Dr. P. K. Patra[2], Devleena Mukherjee[3]

[1]Senior Project Associate, CRISPR Clinical Trials Research Project, Pt. Deendayal Upadhyaya Memorial Health Sciences and Ayush University of Chhattisgarh, India
[2]Vice Chancellor, Pt. Deendayal Upadhyaya Memorial Health Sciences and Ayush University of Chhattisgarh, Raipur, India
[3]Project Associate–I, CRISPR Clinical Trials Research Project, Pt. Deendayal Upadhyaya Memorial Health Sciences and Ayush University of Chhattisgarh, India

Article Info

Article history:

Manuscript ID:

IJPHI0404150421042026
Received: 04-APR -2026
Revised : 15-APR -2026
Accepted: 21-APR -2026
Available online: APR - 2026
DOI:
doi:10.62752/ ijphi.v3i2.246

Keywords:
Sickle Cell Disease, Socio-Economic Status, Tribal Communities, Bastar, Chhattisgarh, Healthcare Access, Social Stigma

****Corresponding Author:***
shahlak781@gmail.com

Abstract

Sickle cell disease (SCD) is a hereditary hemoglobin disorder that is widely prevalent among tribal populations in central India, particularly in the Bastar region of Chhattisgarh. The socioeconomic status (SES) of SCD patients in the state is typically low, with a disproportionate burden on Scheduled Tribes (ST), Scheduled Castes (SC), and Other Backward Classes (OBC), who often reside in remote areas with limited access to healthcare. SCD significantly affects patients' financial stability, quality of life, and access to timely medical care.

This study examines the socioeconomic challenges faced by individuals with SCD in the tribal areas of Bastar, focusing on healthcare access, education, employment status, and social stigma. Using field surveys, interviews, and secondary data analysis, the research highlights the multifaceted impact of SCD on individuals and communities. The findings underscore the urgent need for targeted interventions to enhance healthcare delivery, improve socioeconomic conditions, and reduce disease-related stigma in the region.

1. Introduction

Sickle cell disease (SCD) is a major hereditary hemoglobinopathy and a significant public health concern in India, particularly among tribal and socioeconomically marginalized populations residing in central and eastern regions of the country (Balgir, 2005; Balgir, 2010). 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 within tribal communities (Colah et al., 2015; Hockham et al., 2018). Among these states, Chhattisgarh, especially the Bastar region, represents a critical hotspot for SCD owing to its dense tribal population and persistent structural disadvantages.

SCD disproportionately affects marginalized social groups, 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 (Gupta, 2008; Kumar et al., 2020). These structural inequities not only increase the disease burden but also significantly limit patients' capacity to manage a chronic and debilitating condition. Previous studies have shown that SCD contributes to a reduced quality of life, recurrent morbidity, and increased dependency on family members, thereby reinforcing cycles of socioeconomic vulnerability (Bhagat et al., 2014; Rao et al., 2018).

The Bastar region is home to several tribal communities, including the Gond, Muria, Hill Maria, Bhatara, Dhurva, and Halba tribes, among whom the sickle cell trait (HbAS) has been reported at notably high frequencies, ranging from 15% to 25% in certain subpopulations (Shrivastava et al., 2009; Sickle Cell Disease among Gond Tribe in Chhattisgarh, 2025). These genetically vulnerable populations predominantly inhabit remote, forested, and hilly terrains, where access to basic infrastructure, education, and healthcare facilities remains severely constrained. Although multiple government-led initiatives and screening programs have been introduced, their reach in interior villages remains limited, resulting in delayed diagnosis, underreporting, and suboptimal disease management (NIRTH, 2007; Raman et al., 2021).

Socioeconomic deprivation is a key determinant that shapes the lived experience of SCD in Bastar. A large proportion of affected households depend on subsistence agriculture or daily wage labor, with household incomes often falling below subsistence levels. Gupta (2008) reported that more than 80% of parents of SCD-affected children in central India earn less than ₹4,000 per month, severely limiting their ability to afford transportation, diagnostic tests, and long-term treatment. The chronic and recurrent nature of SCD, characterized by painful vaso-occlusive crises, anemia, increased susceptibility to infections, and frequent hospitalizations, further reduces productivity and imposes substantial financial strain on families (Mohanty et al., 2014; Sareen et al., 2019). Studies have also highlighted the indirect economic burden of SCD due to loss of workdays, reduced earning capacity, and long-term dependency (Holdford et al., 2021).

Educational attainment plays a critical role in influencing disease awareness, healthcare-seeking behavior, and treatment adherence among tribal populations. Literacy rates in remote parts of Bastar are significantly lower than state and national averages, limiting awareness of the genetic basis of SCD and available preventive strategies (NIRTH, 2007; Niranjan et al., 2010). Children with SCD frequently experience school absenteeism due to illness-related fatigue, pain episodes, and hospital visits, leading to poor academic performance and high dropout rates. Low educational levels among caregivers further hinder the timely recognition of symptoms and effective disease management, reinforcing socioeconomic vulnerability across generations (Verma et al., 2017).

Despite ongoing national and state-level initiatives, healthcare access in Bastar remains inadequate. Geographic isolation, poor road connectivity, shortage of trained healthcare professionals, and limited diagnostic facilities contribute to delayed diagnosis and inappropriate treatment of SCD (Colah et al., 2015; Thakur et al., 2017). In many peripheral health centers, confirmatory diagnostic tools, such as hemoglobin electrophoresis or high-performance liquid chromatography, are unavailable, and even basic screening tests are inconsistently implemented. Consequently, SCD symptoms, such as recurrent fever, jaundice, and generalized pain, are often misdiagnosed as infectious or nutritional conditions, delaying appropriate care (Surve et al., 2000; Jain et al., 2012).

In addition to structural and health system barriers, social stigma remains a deeply entrenched challenge for individuals living with SCD in tribal communities. Misconceptions regarding the disease, often attributed to supernatural causes, curses, or hereditary defects, lead to discrimination within families and communities. Traditional healing practices, including faith-based interventions such as *jharfuk*, are commonly sought due to limited biomedical access and low health literacy (Bhat, 2023). Such practices may delay medical intervention and exacerbate disease severity. Stigma also negatively affects marriage prospects, employment opportunities, and social participation, contributing to psychological distress, anxiety, and social isolation among patients (Bhat, 2023; Rao et al., 2018).

The intersection of biological vulnerability, socioeconomic deprivation, inadequate healthcare access, and cultural stigma creates a complex environment in which individuals with SCD in Bastar experience not only physical suffering but also profound social and economic marginalization. While national initiatives, such as the National Sickle Cell Anaemia Elimination Mission, aim to strengthen screening and management, there remains a pressing need for localized, culturally sensitive strategies tailored to the specific realities of tribal regions (Ministry of Tribal Affairs, 2016; Raman et al., 2021). Against this backdrop, the present study examines the socioeconomic status of SCD patients in the tribal areas of Bastar, Chhattisgarh, with a focus on healthcare access, educational attainment, employment patterns, and social stigma. By employing a mixed-methods approach, this research seeks to generate context-specific evidence that can inform policy formulation, improve healthcare delivery, and reduce the social and economic burden of SCD among Chhattisgarh's tribal populations.

2. Literature Review

Sickle cell disease (SCD) has been extensively studied in India because of its high prevalence among tribal and socioeconomically disadvantaged populations. The existing literature consistently documents pronounced disparities in healthcare access, availability of diagnostic services, socioeconomic status, educational attainment, and disease awareness among affected communities (Balgir, 2005; Colah et al., 2015). While national- and state-level studies provide a broad overview of disease distribution and burden, localized and community-specific investigations, particularly in remote tribal regions such as Bastar in Chhattisgarh, remain limited. This gap highlights the need for micro-level socioeconomic assessments to inform culturally appropriate and context-sensitive interventions.

2.1 Prevalence of SCD in India and Tribal Populations

SCD is predominantly concentrated in the central, eastern, and western regions of India, including Chhattisgarh, Madhya Pradesh, Maharashtra, Odisha, Jharkhand, and Gujarat (Balgir, 2010; Jain et al., 2012). Colah et al. (2015), in a comprehensive national review, reported that the frequency of the sickle cell trait (HbAS) among tribal populations ranges from 1% to as high as 40%, depending on the region and ethnic group. These variations have been attributed to long-standing patterns of endogamy, genetic drift, and restricted population mobility within tribal communities (Hockham et al., 2018).

In Chhattisgarh, the prevalence of SCD is particularly high among tribal groups, such as the Gond, Halba, Muria, and Maria communities, which constitute a substantial proportion of the population in the Bastar region (Shrivastava et al., 2009). Studies conducted by the National Institute for Research in Tribal Health (NIRTH) have further indicated that districts, including Bastar, Dantewada, and Bijapur, exhibit some of the highest concentrations of both HbAS and HbSS genotypes in central India (NIRTH, 2007). Despite growing recognition of the disease at the policy level, SCD continues to represent a significant public health challenge owing to the combined influence of genetic susceptibility, environmental conditions, and socioeconomic deprivation.

2.2 Socio-Economic Determinants of SCD Burden

A substantial body of research demonstrates that SCD disproportionately affects populations experiencing chronic poverty, limited education and restricted employment opportunities (Gupta, 2008; Mohanty et al., 2014). Gupta (2008) reported that a majority of tribal households affected by SCD in central India live below the poverty line, with monthly incomes often below ₹4,000. Such financial constraints severely limit access to healthcare services, transportation to tertiary hospitals and long-term treatment adherence.

Comparable findings have been reported from other tribal regions in Odisha and Madhya Pradesh, where households with SCD patients face high out-of-pocket healthcare expenditures and reduced work capacity (Mohanty et al., 2014). Sareen et al. (2019) further emphasized that economic vulnerability contributes to delayed healthcare-seeking behavior, increasing the risk of disease complications that could otherwise be prevented through early intervention. These studies collectively suggest that socioeconomic disadvantage is not merely an outcome of SCD but also a key determinant that exacerbates disease severity and perpetuates intergenerational cycles of poverty.

2.3 Educational Attainment and Awareness Levels

Low educational attainment and limited health literacy are recurring themes in the literature on SCD in tribal populations. In remote tribal regions, inadequate educational infrastructure and high school dropout rates significantly hinder awareness of the genetic nature of SCD and available preventive measures (NIRTH, 2007). Children with SCD frequently experience absenteeism due to illness-related fatigue, pain episodes, and hospitalizations, resulting in poor academic performance and early discontinuation of schooling.

Niranjan et al. (2010) reported that awareness regarding hereditary transmission, premarital screening, and genetic counseling was extremely low among tribal populations in central India. Similarly, Verma et al. (2017) observed that limited health literacy adversely affected treatment adherence and disease management. These findings underscore the importance of educational and community-based awareness interventions in improving preventive and therapeutic outcomes for SCD in tribal settings.

2.4 Healthcare Access and Diagnostic Challenges

Limited access to healthcare services is one of the most consistently documented challenges faced by SCD patients in tribal regions. Colah et al. (2015) and NIRTH (2007) highlighted that many tribal villages are geographically isolated, with poor transportation infrastructure, shortages of trained healthcare professionals, and inadequate diagnostic facilities. In peripheral health centers, confirmatory diagnostic tools, such as hemoglobin electrophoresis or chromatography, are often unavailable, leading to misdiagnosis or delayed diagnosis of SCD.

Studies from Odisha and Maharashtra have reported similar challenges, in which SCD symptoms are frequently mistaken for malaria, nutritional anemia, or recurrent infections in the absence of confirmatory tests (Jain et al., 2012; Surve et al., 2000). The literature consistently points to a disconnect between state-level screening initiatives and the actual availability of diagnostic and treatment services at the grassroots level. This gap is particularly pronounced in remote regions, such as Bastar, emphasizing the need for decentralized diagnostic facilities and enhanced training of frontline healthcare workers.

2.5 Cultural Beliefs, Stigma, and Traditional Healing Practices

Cultural beliefs and social stigma play a critical role in shaping health-seeking behavior among tribal populations affected by SCD. Bhat (2023) documented widespread misconceptions regarding the disease, including the belief that SCD is contagious or results from supernatural causes. Such perceptions contribute to discrimination in social interactions, marriage prospects, and employment opportunities, leading to psychological distress and social isolation among patients.

Traditional healing practices, such as *jharfuk* (faith healing), remain prevalent in the tribal-dominated regions of Chhattisgarh and Odisha. Several qualitative studies have indicated that families often rely on folk healers before seeking biomedical care, delaying effective treatment and potentially worsening disease outcomes (Mohanty et al., 2014). These practices are shaped by deeply rooted cultural norms, limited awareness of genetic inheritance, and restricted access to formal health care services.

2.6 Gaps in the Literature and Need for Localized Studies

Although extensive research exists on SCD in India's tribal populations, most studies focus on broad regional trends rather than localized socioeconomic and cultural contexts. Micro-level investigations specifically addressing the Bastar region remain scarce, despite its unique demographic composition, geographic isolation, and high disease burden. The existing literature highlights the need for localized studies that examine the intersection of socioeconomic conditions, healthcare access, education, and cultural beliefs in shaping the lived experiences of SCD patients.

The literature calls for the following:

1. Detailed socioeconomic profiling of households affected by SCD
2. Assessment of healthcare infrastructure and service accessibility in remote tribal regions
3. Documentation of cultural beliefs, stigma, and community attitudes toward SCD
4. Evaluation of educational and employment outcomes among affected individuals and families

The present study addresses these gaps by providing a focused mixed-methods analysis of the socioeconomic and psychosocial dimensions of SCD in the tribal areas of Bastar, thereby contributing to a more nuanced and context-specific understanding of the disease burden at the community level.

3. Methodology

This study employed a mixed-methods research design to examine the socioeconomic conditions associated with sickle cell disease (SCD) in the tribal areas of Bastar, Chhattisgarh. The study area was purposively selected because of the high prevalence of SCD and persistent limitations in healthcare accessibility. The mixed-methods approach enabled the integration of quantitative socioeconomic indicators with qualitative insights to provide a comprehensive understanding of the issue.

Quantitative data were collected through a structured questionnaire administered to identified SCD patients using purposive and snowball sampling techniques, which are suitable for reaching populations in remote tribal settings. Qualitative data were obtained through semi-structured interviews with a subset of respondents to explore healthcare barriers, socio-cultural beliefs, stigma, and coping mechanisms. In addition, secondary data from government health reports, census records, and peer-reviewed literature were analyzed to contextualize the primary findings. Quantitative data were analyzed using descriptive statistics, whereas qualitative data were examined through thematic analysis. The triangulation of findings enhanced analytical rigor and credibility.

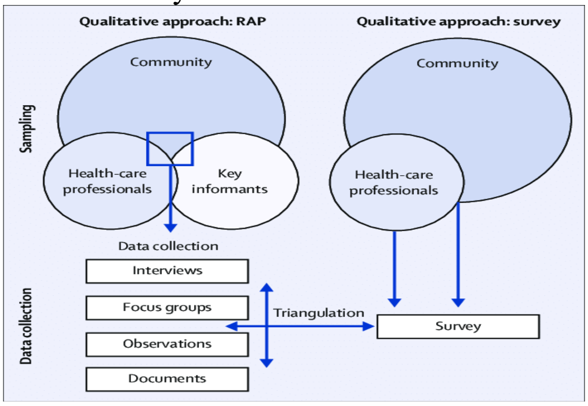

Figure 1 presents the conceptual framework illustrating the mixed-methods data collection and triangulation approach.

3.1 Study Area and Population

This study was conducted in selected tribal-dominated villages in the Bastar district, characterized by dense forests, hilly terrain, limited connectivity, and a predominantly tribal population. Major tribal communities in the region include the Gond, Muria, Hill Maria, Bhatara, Dhurva, and Halba groups, all of whom exhibit a high prevalence of the sickle cell gene.The study population included individuals diagnosed with SCD (HbSS) and sickle cell trait carriers (HbAS), as identified through local healthcare workers, primary health centers, and village-level health records. Only permanent residents of the selected villages were included in the study.

3.2 Research Design: Mixed-Methods Approach

A mixed-methods design was adopted to strengthen the robustness of the findings. Quantitative methods were used to assess patterns in education, employment, healthcare access, and income, whereas qualitative methods provided insights into lived experiences, stigma, cultural beliefs, and healthcare-seeking behavior. The integration of these approaches allowed for a nuanced interpretation of the socioeconomic and psychosocial dimensions of SCD.

3.3 Quantitative Component

3.3.1 Sampling Technique

Given the exploratory nature of the study and the difficulty in accessing the target population, a total of 150 respondents were included in the quantitative survey. This sample size is consistent with previous socioeconomic studies on SCD in tribal regions and is considered adequate for descriptive analysis.

3.3.2 Questionnaire Design

The questionnaire covered the following domains.

- Demographic characteristics
- Socio-economic status
- Healthcare access and utilization
- Educational attainment
- Social stigma and psychosocial impact

Closed-ended and Likert-scale items facilitated quantitative analysis, whereas limited open-ended responses provided contextual clarification.

3.3.3 Data Collection Procedure

Data were collected through face-to-face interviews conducted in local dialects by trained field investigators familiar with the cultural context. This approach ensured clarity and accuracy, given the low literacy levels of the respondents.

3.4 Qualitative Component

Semi-structured interviews were conducted with 20 participants who were purposively selected to capture diverse experiences across age, gender, disease severity, and socioeconomic background. The interviews explored perceptions of SCD, healthcare experiences, stigma, economic challenges, and coping strategies. The transcribed data were analyzed using thematic coding.

3.5 Secondary Data Sources

Secondary data were drawn from

- Government reports and policy documents
- Census and district-level socio-economic data
- Peer-reviewed literature on SCD in tribal populations

These sources provided contextual support and strengthened the interpretation of the primary findings.

3.6 Data Analysis

Quantitative data were analyzed using descriptive statistics, including frequencies, percentages, and cross-tabulations. Qualitative data were analyzed thematically, with recurring patterns grouped into domains related to healthcare access, socioeconomic constraints, cultural beliefs, stigma, and coping mechanisms. The findings were triangulated to improve reliability.

3.7 Methodological Strengths

Methodological approach:

- Integrates quantitative and qualitative evidence
- Captures socio-economic and psychosocial dimensions
- Uses triangulation to enhance analytical robustness

- Generates context-specific insights relevant for policy and program development

4. Results

4.1 Access to Healthcare Services

Only 24.06% of respondents reported satisfactory access to preventive and treatment services for SCD. Geographic remoteness, absence of specialized healthcare facilities, inadequate transportation, and financial constraints emerged as the principal barriers to healthcare utilization. Although government and non-governmental programs operate in the region, their effectiveness remains limited due to infrastructural gaps, irregular service delivery, and difficulty in reaching remote tribal settlements.

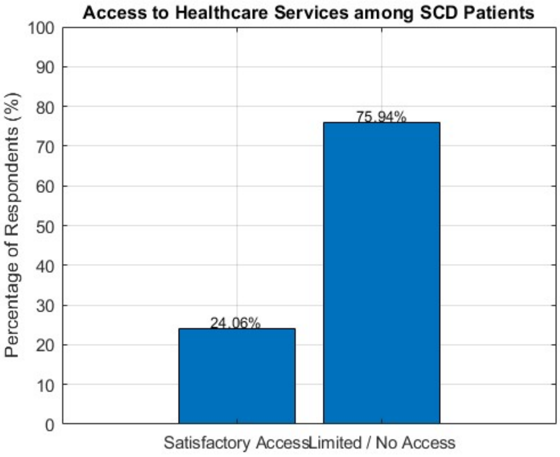

Figure 2. Distribution of access to healthcare services among individuals with sickle cell disease in tribal areas of Bastar, Chhattisgarh

Figure 2 illustrates the distribution of access to healthcare services among individuals with sickle cell disease in the tribal areas of Bastar, Chhattisgarh. The findings indicate that only 24.06% of respondents reported having satisfactory access to preventive and treatment services, whereas a substantial majority (75.94%) experienced limited or no access to adequate healthcare. This pronounced disparity highlights the persistent gaps in healthcare infrastructure and service delivery in remote tribal regions. Factors, such as geographic isolation, lack of specialized medical facilities, inadequate transportation, and financial constraints, significantly restrict healthcare utilization. Despite the presence of government and non-governmental health initiatives, their reach and effectiveness remain insufficient to meet the needs of the majority of the affected population, underscoring the urgency for targeted and decentralized healthcare interventions.

4.2 Educational Attainment

Educational attainment among SCD patients and their family members was markedly low; 48.5% of respondents reported no formal education. Frequent illness episodes, chronic pain, and recurrent hospitalizations contributed to school absenteeism and early dropout, particularly among children and adolescents. Low literacy levels further constrained health awareness, treatment adherence, and access to stable employment, reinforcing intergenerational cycles of socioeconomic vulnerability.

4.3 Employment Status and Economic Impact

Most respondents were engaged in low-paying, labor-intensive occupations, primarily in agriculture and daily wage work. Disease-related physical limitations led to irregular employment, reduced productivity, and income loss, increasing financial dependence on family members. Healthcare-related expenditures imposed an additional burden, with treatment and associated costs accounting for an estimated 14–15% of annual household income, consistent with findings from comparable studies.

4.4 Social Stigma and Psychosocial Consequences

Social stigma associated with SCD emerged as a significant challenge within tribal communities. Respondents reported negative impacts on marriage prospects, social participation, and employment opportunities. Persistent misconceptions portraying SCD as a contagious condition or a supernatural affliction contributed to discrimination and social exclusion. Consequently, many patients experienced psychological distress, anxiety, and social isolation, adversely affecting their overall quality of life.

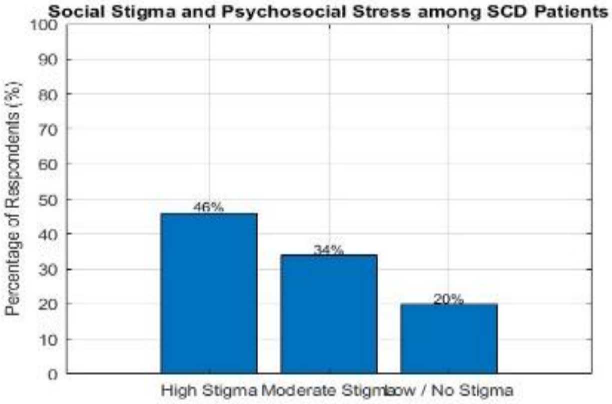

Figure 3: Distribution of social stigma and psychosocial stress among individuals with sickle cell disease in the tribal areas of Bastar, Chhattisgarh.

Figure 3 presents the distribution of social stigma and psychosocial stress among SCD patients in the tribal areas of Bastar, Chhattisgarh. Nearly half (46 %) of the respondents reported experiencing high levels of social stigma, while 34% indicated moderate stigma. Only 20% of the participants reported low or no stigma. These findings reveal that a substantial proportion of individuals living with SCD experience persistent social discrimination and psychosocial stress within their communities. Deep-rooted misconceptions regarding the hereditary nature of the disease, along with beliefs linking SCD to contagion or supernatural causes, contribute to social exclusion, reduced marriage prospects, and restricted participation in community life. The high prevalence of stigma underscores the critical need for culturally sensitive awareness programs, psychosocial counseling, and community engagement initiatives to address misinformation and improve the overall quality of life of individuals affected by SCD.

Table 1. Socioeconomic and Healthcare Indicators in the Study Population

S. No	Parameter	Remarks/Implications
1	Healthcare Access	Indicates major gaps in healthcare infrastructure and outreach
2	Educational Attainment	Limits health awareness and employment opportunities
3	Employment Status	Contributes to economic vulnerability and restricted healthcare access
4	Social Stigma	Affects mental well-being and healthcare-seeking behavior
5	Mental Health Impact	Highlights need for community mental health support

Table 1 summarizes the key socioeconomic and healthcare indicators for the study population. Access to basic healthcare services was reported by only 24.06% of respondents, highlighting substantial gaps in infrastructure and outreach in remote tribal areas. Educational attainment was poor, with nearly half of the respondents lacking formal education, which limited disease awareness and employment opportunities. Employment patterns reflected economic vulnerability, as most participants were engaged in low-paid manual labor. Social stigma and associated psychological stress were prominent, underscoring the need for integrated medical and psychosocial support mechanisms.

5. Discussion

The findings reveal that individuals living with SCD in the Bastar region experience a complex and interrelated set of socioeconomic, cultural, and healthcare challenges rooted in structural inequalities affecting tribal communities. The limited availability and accessibility of healthcare services significantly hinder timely diagnosis and effective disease management. Dependence on under-resourced primary health centers, coupled with shortages of trained personnel and diagnostic facilities, contributes to misdiagnosis and delayed treatment, worsening health outcomes, and increasing household burdens.

Low literacy levels among patients and caregivers further exacerbate these challenges by limiting awareness of the genetic nature of SCD, the importance of early diagnosis, and the need for sustained medical follow-up. This knowledge gap encourages reliance on traditional healing practices, which, while culturally embedded, may delay biomedical intervention and aggravate disease complications.

Economic insecurity is another major constraint. The physical demands of agricultural and manual labor, combined with disease-related fatigue and pain, reduce the work capacity and income stability of these individuals. This economic vulnerability reinforces cycles of poverty and limits access to consistent healthcare, echoing the findings from other tribal regions in India.

Social stigma remains one of the most pervasive and damaging factors influencing the lived experience of SCD. Misconceptions about the disease lead to discrimination, social exclusion, and diminished marriage prospects, contributing to psychological distress and reduced healthcare-seeking behavior. These interconnected challenges demonstrate that the burden of SCD in Bastar extends beyond biological illness, encompassing broader social and economic marginalization.

6.CONCLUSION AND FUTURE DIRECTIONS

Sickle cell disease (SCD) remains a significant public health challenge in the Bastar region of Chhattisgarh, disproportionately affecting tribal communities burdened by socioeconomic disadvantage. The findings of this study demonstrate that the impact of SCD extends beyond its biological manifestations, encompassing profound challenges related to healthcare access, educational attainment, employment stability, and social inclusion. The limited availability of diagnostic and treatment facilities, compounded by geographic isolation and financial constraints, continues to delay timely diagnosis and effective disease management. Low literacy levels and inadequate health awareness further restrict healthcare utilization and contribute to poor treatment adherence.

Economic vulnerability emerged as a central concern, as disease-related physical limitations reduce work capacity and income security among individuals primarily engaged in labor-intensive occupations. These constraints, combined with substantial healthcare-related expenditures, reinforce cycles of poverty at the household level. Social stigma associated with SCD remains deeply entrenched, adversely affecting marriage prospects, employment opportunities, and social participation, while contributing to psychological distress and social isolation. Collectively, these interconnected factors highlight the need for holistic approaches that address both the medical and social determinants of health.

Future efforts to mitigate the burden of SCD in tribal regions, such as Bastar, should prioritize strengthening healthcare infrastructure through decentralized diagnostic services, mobile health units, and capacity building of frontline healthcare workers. Community-based educational initiatives aimed at improving health literacy, promoting awareness of the genetic nature of SCD, and encouraging early screening and sustained treatment are equally important. Livelihood and skill-development programs tailored to the physical capacities of SCD patients can help reduce economic dependency and improve quality of life. Addressing stigma requires culturally sensitive engagement with community leaders, educators, and traditional healers to dispel misconceptions and promote social inclusion.

Further research should focus on longitudinal assessments of disease progression and socioeconomic outcomes, evaluation of community-based healthcare delivery models, and detailed analysis of the economic burden and cost-effectiveness of preventive interventions. Integrating psychosocial support into existing health programs and empowering community health workers may offer sustainable pathways for improving outcomes. Overall, context-specific, community-centered strategies are essential for translating national policy initiatives into meaningful improvements in the lives of SCD-affected tribal populations.

7. Acknowledgements

The authors sincerely acknowledge the **Department of Science and Technology (DST), Government of India**, for providing financial support that enabled the successful completion of this study. The DST's continued efforts to foster scientific innovation and translational research are deeply appreciated.

The authors express their gratitude to **Dr. Debjyoti Chakraborty**, Principal Scientist at the **CSIR–Institute of Genomics and Integrative Biology (CSIR-IGIB)**, for his expert guidance, valuable scientific perspectives, and constant encouragement throughout the study. His mentorship played a significant role in shaping the research framework and strengthening the overall execution of the project.

The authors also convey their sincere appreciation to the **Hon'ble Vice Chancellor of Pt. Deendayal Upadhyay Memorial Health Sciences and AYUSH University of Chhattisgarh, Raipur**, for providing institutional support, encouragement, and an enabling academic environment that facilitated the completion of this study.

Special thanks are extended to **Mr. Thaneshwar Kumar Sahu**, Consultant, Teacher Training Institute, **Pt. Deendayal Upadhyay Memorial Health Sciences and AYUSH University of Chhattisgarh, Raipur**, for his valuable technical assistance and continuous support during various stages of the project implementation.

The authors express their gratitude to all individuals and institutions whose contributions, either directly or indirectly, supported and enriched this research endeavor.

Informed Consent

Not Applicable.

FUNDING

No funding was received for this study.

Conflict of Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper. The authors declare no conflict of interest among themselves. The authors alone are responsible for the content and writing of this article.

Financial Interests

The authors declare they have no financial interests.

Human and Animal Rights

NA

Ethics approval and consent to participate

Not applicable.

References

1. Balgir, R. S. (2005). The burden of hemoglobinopathies in India and the challenges ahead. *Current Science, 88*(6), 915–918.
2. Balgir, R. S. (2010). Genetic epidemiology of sickle cell disease in India. *Journal of the Indian Anthropological Society, 45*, 1–14.
3. Bartolucci, P., & Galactéros, F. (2012). Clinical management of adult sickle-cell disease. *Current Opinion in Hematology, 19*(3), 149–155. https://doi.org/10.1097/MOH.0b013e328351c35f
4. Bhagat, V., Baviskar, S., Mudey, A., & Goyal, R. (2014). Poor health-related quality of life among patients with sickle cell disease. *Indian Journal of Palliative Care, 20*(2), 107–111. https://doi.org/10.4103/0973-1075.132622

5. Bhat, D. (2023). Stigma and psychosocial challenges in sickle cell disease among Indian tribal populations. *Journal of Public Health*.
6. Chauhan, P. (2012). Maternal mortality among tribal women at a tertiary level of care in Bastar, Chhattisgarh. *Journal of Health & Population in Developing Countries, 15*(1), 1–6.
7. Colah, R. B., Mukherjee, M. B., Martin, S., & Ghosh, K. (2015). Sickle cell disease in tribal populations in India. *Indian Journal of Medical Research, 141*(5), 509–515.
8. Gupta, R. B. (2008). Sickle cell disease in central India: Need for micro-level studies. *NIRTH Bulletin, 13*(1–2), 1–4.
9. Hockham, C., Bhatt, S., Colah, R., et al. (2018). The spatial epidemiology of sickle-cell anaemia in India. *Scientific Reports, 8*(1), 17685. https://doi.org/10.1038/s41598-018-36077-w
10. Holdford, D., Vendetti, N., Sop, D. M., Johnson, S., & Smith, W. R. (2021). Indirect economic burden of sickle cell disease. *Value in Health, 24*(8), 1095–1101. https://doi.org/10.1016/j.jval.2021.02.014
11. Inusa, B. P. D., Hsu, L. L., Kohli, N., et al. (2019). Sickle cell disease—Genetics, pathophysiology, clinical presentation and treatment. *International Journal of Neonatal Screening, 5*(2), 20. https://doi.org/10.3390/ijns5020020
12. Jain, D., Italia, K., Sarathi, V., & Colah, R. B. (2012). Sickle cell disease in tribal populations of India: A systematic review. *Indian Journal of Medical Research, 136*(3), 403–412.
13. Kshirsagar, A. Y., Patil, S., Patil, P., & Patil, N. (2016). Socioeconomic impact of sickle cell disease on families in India. *Journal of Family Medicine and Primary Care, 5*(2), 396–399.
14. Kumar, M. M., Pathak, V. K., & Ruikar, M. (2020). Tribal population in India: A public health challenge and road to future. *Journal of Family Medicine and Primary Care, 9*(2), 508–512. https://doi.org/10.4103/jfmpc.jfmpc_992_19
15. Leeflang, M. M. G., Bossuyt, P. M. M., & Irwig, L. (2009). Diagnostic test accuracy may vary with prevalence: Implications for evidence-based diagnosis. *Journal of Clinical Epidemiology, 62*(1), 5–12. https://doi.org/10.1016/j.jclinepi.2008.04.007
16. Ministry of Tribal Affairs, Government of India. (2016). *National sickle cell anaemia elimination mission*. Government of India. https://sickle.nhm.gov.in
17. Ministry of Tribal Affairs, Government of India. (2021). *Tribal health action plan*. Government of India.
18. Mohanty, D., Colah, R. B., Gorakshakar, A., & Patel, R. (2014). Burden of sickle cell disease in tribal communities of India. *Indian Pediatrics, 51*, 101–105.
19. National Health Mission. (2019). *Guidelines for prevention and control of hemoglobinopathies in India*. Ministry of Health & Family Welfare, Government of India.
20. National Institute for Research in Tribal Health. (2007). *Tribal health bulletin*. Jabalpur, India: NIRTH Publications.
21. National Institute for Research in Tribal Health. (2018). *Sickle cell disease control programme in Chhattisgarh*. Jabalpur, India: NIRTH.
22. Niranjan, R., Sahu, P., & Patel, M. (2010). Awareness and perception of sickle cell disease among tribal populations. *Journal of Genetic Counseling, 19*(3), 291–298.
23. Piel, F. B., Patil, A. P., Howes, R. E., Nyangiri, O. A., Gething, P. W., Dewi, M., Temperley, W. H., Williams, T. N., Weatherall, D. J., & Hay, S. I. (2013). Global epidemiology of sickle haemoglobin in neonates. *The Lancet, 381*(9861), 142–151.
24. Raman, V., Seshadri, T., Joice, S. V., & Srinivas, P. N. (2021). Sickle cell disease in India: A scoping review from a health systems perspective to identify an agenda for research and action. *BMJ Global Health, 6*(2), e004322. https://doi.org/10.1136/bmjgh-2020-004322
25. Rao, S., Subhashini, J., & Reddy, B. M. (2018). Quality of life among patients with sickle cell disease in India. *Indian Journal of Hematology and Blood Transfusion, 34*(3), 455–461.
26. Sareen, N., Gupta, S., & Singh, A. (2019). Socioeconomic burden of sickle cell disease in tribal regions of India. *Journal of Community Health, 44*(2), 367–374.
27. Shrivastava, P. K., Bansal, A. K., & Kantharaj, C. S. (2009). Incidence of sickle cell disorder among tribal and non-tribal communities of Bastar, India. *Research Journal of Science and Technology, 1*(1), 33–34.
28. Singh, P., & Deorari, A. K. (2018). Challenges in implementation of sickle cell disease screening programs in India. *Indian Pediatrics, 55*(8), 669–672.
29. Sickle cell disease among Gond tribe in Chhattisgarh. (2025). *International Journal of Reviews and Research in Social Sciences*.
30. Sundd, P., Gladwin, M. T., & Novelli, E. M. (2019). Pathophysiology of sickle cell disease.

Annual Review of Pathology: Mechanisms of Disease, 14, 263–292. https://doi.org/10.1146/annurev-pathmechdis-012418-012838

31. Surve, R. R., Mukherjee, M. B., Kate, S. L., et al. (2000). Detection of the beta-S gene: An evaluation of the solubility test against automated chromatography and haemoglobin electrophoresis. *British Journal of Biomedical Science, 57*(4), 292–294.
32. Thakur, A., Sharma, R., & Verma, S. (2017). Barriers to healthcare access among tribal populations in central India. *Journal of Public Health Policy, 38*(4), 513–528.
33. Thomson, A. M., McHugh, T. A., Oron, A. P., et al. (2023). Global, regional, and national prevalence and mortality burden of sickle cell disease, 2000–2021: A systematic analysis from the Global Burden of Disease Study 2021. *The Lancet Haematology*. https://doi.org/10.1016/S2352-3026(23)00118-7
34. Weatherall, D. J., & Clegg, J. B. (2001). Inherited haemoglobin disorders: An increasing global health problem. *Bulletin of the World Health Organization, 79*(8), 704–712.
35. World Bank. (2018). *Poverty and health in tribal regions of India*. World Bank Publications.
36. World Health Organization. (2016). *Framework on integrated, people-centred health services*. WHO.