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GOVERNANCE, SOCIO-ECONOMIC FACTORS, AND HEMOGLOBINOPATHIES: ADDRESSING HEALTH DISPARITIES IN TRIBAL COMMUNITIES

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ABSTRACT
Hemoglobinopathies, including sickle cell disease and thalassemias, are inherited blood disorders that disproportionately affect tribal and marginalized populations globally. These conditions impose significant health burdens characterized by chronic anemia, pain crises, organ damage, and premature mortality. The complexity of managing hemoglobinopathies in underserved communities is compounded by socio-economic disparities, limited healthcare access, cultural barriers, and systemic governance challenges. This manuscript explores the critical role of governance and socio-economic determinants in shaping health outcomes related to hemoglobinopathies among tribal populations. A mixed-methods approach, integrating epidemiological data, qualitative insights, and policy analysis, highlights how political commitment and resource allocation directly influence screening programs, diagnostic capacity, treatment availability, and community engagement. Socio-economic factors such as poverty, low education, malnutrition, and migration patterns further affect disease prevalence, healthcare utilization, and treatment adherence. The interplay of these factors perpetuates cycles of disease and socio-economic disadvantage in tribal areas. Global demographic shifts and increasing migration necessitate harmonized international policies and innovative interventions. Digital health technologies, telemedicine, and community-based data platforms offer promising avenues to bridge healthcare gaps. India's national sickle cell elimination mission exemplifies political will but also reveals ongoing challenges in neonatal screening, care continuity, and data systems. The manuscript emphasizes the need for integrated, culturally sensitive, and multi-sectoral strategies that empower tribal communities and strengthen health systems. Closing governance and socio-economic gaps is essential to mitigate the burden of hemoglobinopathies and advance health equity globally. Future research should focus on evaluating policy impacts, scaling best practices, and fostering sustainable community partnerships.

KEYWORDS: Hemoglobinopathies, Sickle Cell Disease, Tribal Health, Governance, Socio-economic Determinants.

INTRODUCTION
As global health priorities shift from communicable to non-communicable diseases, inherited blood disorders have emerged as a significant public health concern, particularly in resource-limited and socio-politically marginalized populations. The intricate interplay between governance and socio-economic status is especially pronounced in tribal communities confronting abnormal hemoglobinopathies. These disorders disproportionately burden underserved groups such as tribal and indigenous populations, where structural inequities—including limited access to diagnostic and treatment services, social stigma, and environmental stressors—worsen health outcomes.

Additionally, increasing global migration and intermarriage are reshaping the epidemiology of hemoglobinopathies, underscoring the need for cross-border cooperation and harmonized international health policies. Governance plays a crucial role in shaping these outcomes. When political power aligns with health equity goals, it can drive transformative improvements in hemoglobinopathy care through universal screening programs, the establishment of regional centers of excellence, and subsidized treatment initiatives. On the other hand, when long-term political commitment is lacking, vulnerable communities often continue to face interconnected challenges of illness, poverty, and marginalization. The application of political influence—through the creation of policies, allocation of resources, and execution of health programs—plays a vital role in determining health outcomes and enhancing the quality of life for these disadvantaged groups.[1]

Despite being preventable and manageable through early screening, genetic counseling, and comprehensive care, hemoglobinopathies continue to impose a substantial burden due to systemic healthcare gaps, insufficient funding, and policy neglect. Disorders such as sickle cell disease and thalassemia are highly prevalent in tribal regions and are further exacerbated by restricted healthcare access, nutritional deficiencies, and environmental challenges.[2] These genetic conditions, characterized by abnormal hemoglobin production, cause chronic anemia, painful crises, organ damage, and shortened life expectancy, impeding socio-economic advancement and perpetuating poverty cycles.[3,4] Addressing these multifaceted challenges requires a holistic approach integrating political will, evidence-based interventions, and socially inclusive development strategies. Relevant literature addressing these fundamental issues is summarized in Table 1.[4–10]

Table 1: Summary of Key Studies on Tribal Health and Hemoglobinopathies.

Author(s)	Study Focus / Title	Main Findings	Relevance to Tribal Health & Hemoglobinopathies	Implications
Gram L et al. 2019	Promoting women's and children's health through community groups	Community groups improve health through education, support, and local engagement.	Demonstrates community-led solutions are effective in low-resource settings, including tribal areas.	Encourages use of community health models to manage hemoglobinopathies.
Haddad et al. 2012	Health divide between indigenous and non-indigenous populations in Kerala	Indigenous groups have poorer health outcomes and access despite overall state health progress.	Confirms persistent disparities in health status and access.	Targeted policies and culturally inclusive services are needed.
Kaufman, 1999	Hematology: Synthesis of sickle and normal hemoglobins	Outlines the biological mechanisms and clinical significance of hemoglobinopathies.	Provides foundational biomedical context for diagnosis and treatment.	Diagnostic access and disease management protocols are essential in tribal settings.
Keikelame & Swartz, 2019	Decolonising research methodologies	Emphasizes the importance of culturally respectful research and healthcare practices.	Highlights relevance of local traditions and beliefs in tribal health settings.	Supports use of culturally sensitive and participatory research approaches.
George et al. 2020	Barriers to healthcare access in Attapadi tribal region, Kerala	Despite free healthcare, utilization remains low due to mistrust and cultural disconnection.	Demonstrates that availability doesn't equal access for tribal populations.	Trust-building, cultural competence, and provider training are essential.
Colah R et al. 2015	Hemoglobinopathies in Indian tribal populations: prevalence, genetics, clinical management, and research needs	HbD not widely reported; sickle cell hemoglobin (HbS) is predominant among tribal groups, mainly linked to Arab-India haplotype. Severity varies due to genetic factors like haplotypes and α-thalassaemia co-inheritance. High fetal hemoglobin modulates disease severity, with heterogeneity among tribes. Large-scale micro-mapping of HbS prevalence lacking. Migration patterns are changing epidemiology.	Provides a comprehensive overview of hemoglobinopathy burden, genetics, clinical variability, and health system gaps in tribal India. Highlights the complexity of genetic and environmental factors influencing disease.	Emphasizes need for improved healthcare infrastructure, national registry, targeted screening, genetic counseling, and focused research to inform policy and clinical management tailored for tribal populations.
Sahu M. et al. 2023	Tribal Health: A Public Health Exigency and Road Map to Future	Highlights persistent health disparities among tribal populations due to socio-economic marginalization, poor infrastructure, and cultural barriers. Emphasizes the urgent need for integrated policy, healthcare access improvement, and community-based interventions. Calls for focused research, improved governance, and use of technology to bridge health gaps.	Provides a comprehensive overview of the multifactorial challenges impacting tribal health, including genetic disorders like hemoglobinopathies.	Advocates for multi-sectoral collaboration, culturally sensitive health programs, and adoption of innovative healthcare delivery models to improve tribal health outcomes.

METHODOLOGY

This study will employ a mixed-methods research design to investigate the global impact of governance and socio-economic determinants on the prevalence, access to care, and outcomes associated with hemoglobinopathies in tribal and underserved populations. By integrating quantitative and qualitative approaches, the study aims to offer a holistic understanding of the systemic and cultural factors shaping the burden and management of these genetic disorders worldwide.[10]

The quantitative component will utilize a variety of secondary data sources, including the Global Burden of Disease (GBD) Study, WHO Global Health Observatory, Demographic and Health Surveys (DHS), World Bank databases, and national health registries. Epidemiological variables such as the prevalence, incidence, and mortality rates of hemoglobinopathies—specifically sickle cell disease, β-thalassemia, HbE, and HbC—will be analyzed alongside socio-economic indicators, including income levels, education, and access to clean water and healthcare. Health system variables such as proximity to diagnostic facilities, availability of trained healthcare personnel, and the presence of disease-specific programs will also be considered. Additionally, governance-related indicators, such as health expenditure, decentralization of services, and the existence of national hemoglobinopathies policies, will be assessed. Data analysis will include descriptive statistics, multivariable regression modeling, and geospatial mapping using GIS to identify regional disparities and patterns of disease burden and healthcare access.

The qualitative component will be conducted using purposive sampling in selected countries across Africa, Asia, and Latin America. Participants will include individuals and families affected by hemoglobinopathies, healthcare providers, community health workers, tribal leaders, and government officials. In-depth interviews and focus group discussions will be carried out to explore lived experiences, perceived barriers to healthcare, cultural beliefs, stigma, and trust in health systems. Key informant interviews with policymakers and program managers will provide insights into policy formulation, resource allocation, and implementation challenges. All qualitative data will be analyzed thematically using NVivo or similar software, guided by frameworks such as the WHO Health Systems Framework and the Health Policy Triangle.

In addition to primary data collection, a policy and document review will be undertaken to evaluate the alignment of national and regional health policies with global recommendations such as those from the WHO and the Sustainable Development Goals (SDGs). This will involve analyzing national health plans, disease-specific strategies, budget allocations, and evaluation reports to assess inclusivity, funding sustainability, and accountability mechanisms. Special attention will be given to the integration of hemoglobinopathies within universal health coverage (UHC) frameworks and national non-communicable disease (NCD) action plans.

An intersectional and comparative analysis will be performed to identify the compounded vulnerabilities that arise from factors such as gender, ethnicity, socio-economic status, and geography. This analysis will facilitate a nuanced understanding of how overlapping social determinants influence disease exposure, healthcare access, and health outcomes. Comparisons will be drawn between low-income countries (e.g., Nigeria, Bangladesh), middle-income nations (e.g., India, Indonesia, Egypt), and marginalized groups within high-income countries.

The outcomes of this study will be evaluated across several domains. Epidemiological analysis will highlight disease hotspots and care disparities, while policy review and stakeholder interviews will identify strengths and gaps in health governance. The intersectional analysis will expose health inequities across subgroups, and qualitative findings will offer culturally rich insights into barriers and facilitators of care. Together, these results will inform the development of a comprehensive, evidence-based strategy toolkit adaptable to national and regional contexts for improving the prevention, diagnosis, and management of hemoglobinopathies in marginalized populations.[11-13]

Bridging Gaps in Sickle Cell Care: The Governance and Socio-Economic Lens

Role of Governance

Policy Implementation: National programs for screening, early diagnosis, and genetic counseling requires political will and coordinated policy execution.

Health Financing: Allocation of government funds determines availability of diagnostic tools, essential medicines (like folic acid), and trained healthcare personnel.

Registry and Surveillance Systems: Countries with better governance often maintain national registries that help track hemoglobinopathy prevalence and outcomes, guiding targeted interventions.'

Decentralization and Local Inclusion: In tribal areas, decentralized healthcare governance improves community engagement and delivery of culturally sensitive care.

2. Importance of Socio-Economic Factors

Access to Healthcare: People in lower SES groups, especially in tribal and rural regions, often lack access to specialized centers for hemoglobinopathies screening and treatment.

Health Literacy: Low education levels can hinder understanding of genetic inheritance, treatment regimens, and importance of follow-up care.

Nutrition and Comorbidities: Poor socio-economic conditions lead to malnutrition, which can worsen the clinical severity of hemoglobinopathies and increase vulnerability to infections.

Migration and Urbanization: Economic pressures push tribal populations into urban slums, changing the disease geography and placing stress on underprepared urban health systems.

Intersection of Governance and Socio-Economics
When governance is weak and socio-economic conditions are poor.

- Diseases go undiagnosed or are misdiagnosed.
- Preventable complications occur due to lack of screening, counseling, or treatment.
- Stigma and myths about hereditary disorders prevail due to low public awareness.
- Healthcare services are underutilized, even when available, due to distrust or cultural disconnect.

Conversely, strong governance and socio-economic development can:

- Promote early diagnosis and prevention through school-based or antenatal screening.
- Enable health equity through subsidized treatment programs.
- Encourage community engagement and culturally informed care strategies.
- Improve data-driven policy making using registries and surveillance systems.

DISCUSSION

Political power can be strategically harnessed to reduce socio-economic disparities in tribal communities through several key mechanisms. First, comprehensive policy reforms are essential to enhance access to critical healthcare services, including systematic screening, early diagnosis, and evidence-based treatment for hemoglobinopathies. Second, equitable and targeted resource allocation should prioritize investments in public health infrastructure, capacity-building of the healthcare workforce, and the implementation of community-based health programs tailored to local needs.[14]

Third, sustained advocacy efforts are crucial to raising awareness among policymakers and the general public about the unique health challenges confronting tribal populations.[14] Such advocacy can generate political momentum and facilitate the mobilization of both financial and institutional support. Furthermore, empowering communities through participatory decision-making processes ensures that interventions are culturally sensitive, sustainable, and aligned with the needs and values of the population. Integrating traditional medical practices within modern healthcare delivery systems may also enhance community acceptance and improve health outcomes.

India stands out as one of the few countries to have launched a dedicated national elimination mission for sickle cell disease, reflecting strong political commitment. However, there remains a pressing need to strengthen neonatal screening programs, ensure continuity of care, establish robust national registries, and enhance patient follow-up systems. Reported papers highlight the incidence and complications of pregnancy in women with sickle cell disease, emphasizing the need for specialized prenatal care to reduce maternal and fetal morbidity.[15] Other studies report comprehensive strategies to address anemia in women of reproductive age, focusing on interventions applicable to those with hemoglobinopathies such as sickle cell anemia.[16-17] While India's targeted focus on tribal populations is commendable—particularly considering the genetic and geographic variability of sickle cell disease—significant implementation barriers persist and must be systematically addressed to achieve equitable health outcomes.

Tribal health and development are deeply influenced by socio-cultural dimensions that shape health behaviors, access, and outcomes.[18] Addressing broader social determinants—such as poverty, malnutrition, and low education—requires a cross-sectoral strategy, as these factors significantly influence healthcare utilization and expenditure among aboriginal and tribal populations.[19] Understanding the burden of anemia and hemoglobinopathies globally and nationally is essential for developing targeted, evidence-based health policies and improving outcomes in underserved regions.[20] Technological innovations, such as mobile health tools, telemedicine, and community-based data platforms, offer promising solutions to improve healthcare access and efficiency in low-resource settings.[21]

Sustained political commitment, combined with community engagement and multi-sectoral collaboration, is necessary to promote equitable health outcomes in indigenous communities.[22] Collaborating with tribal leaders and incorporating local knowledge enhances the cultural appropriateness, relevance, and acceptability of health programs. Finally, improving educational outcomes, especially in tribal areas, is critical, as low literacy remains a persistent barrier to health awareness, preventive care, and treatment adherence.[23]

CONCLUSION

Hemoglobinopathies, including sickle cell disease and thalassemias, remain a critical global health challenge, disproportionately affecting tribal and marginalized populations. The burden of these inherited disorders is amplified by socio-economic disparities, limited healthcare access, and systemic governance shortcomings. Structural barriers such as inadequate diagnostics, poor health infrastructure, low health literacy, and cultural stigmas further exacerbate health outcomes in these communities. Effective governance plays a vital role in shaping disease control through

policy development, resource allocation, and program implementation. Political commitment is essential for establishing universal screening, strengthening healthcare workforce capacity, and fostering community engagement. Integrating traditional medicine with modern healthcare can enhance cultural acceptability and program sustainability. Socio-economic factors—including poverty, malnutrition, education deficits, and migration—significantly influence disease prevalence, severity, and healthcare utilization. Addressing these requires cross-sectoral strategies that extend beyond healthcare, incorporating education, nutrition, and social welfare. Globally, demographic shifts and migration patterns are changing the epidemiology of hemoglobinopathies, highlighting the need for international cooperation and harmonized policies. Innovative solutions such as mobile health technologies, telemedicine, and robust national registries are critical for improving care delivery and disease monitoring. India's national sickle cell elimination mission demonstrates political will but underscores challenges in neonatal screening, care continuity, and data systems. Targeted, culturally sensitive interventions and capacity building in tribal areas are crucial to overcoming these barriers. In conclusion, bridging governance and socio-economic gaps is essential for reducing the burden of hemoglobinopathies and achieving health equity in tribal and vulnerable populations worldwide. Future efforts must emphasize evidence-based policies, community empowerment, and multi-sectoral collaboration.

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Abbreviations: GBD: Global Burden of Disease; WHO: World Health Organization; DHS: Demographic and Health Surveys; GIS: Geographic Information System, UHC: Universal Health Coverage, NCD: Non-Communicable Disease, SES: Socio-Economic Status.

REFERENCES

1. Amid A, Saliba AN, Taher A, Klaassen RJ. Thalassaemia in children: from quality of care to quality of life. Arch Dis Child, 2015; 100(11): 1051.
2. Araujo CM, Ferreira BES, Meira MSJN, Mucuta NJ, Andrade RRG, Oliveira THC, et al. Knowledge and practice of nursing in sickle cell disease and hemoglobinopathies in primary care. Texto Contexto Enferm. 2023; 32.
3. Bhoi N, Acharya SK. Health status of particularly vulnerable tribal groups (PVTGs) of Odisha: a narrative review. J Health Popul Nutr, 2024; 43(1).
4. Buser JM. The need for hematology nurse education in low- and middle-income countries: A community case study in Tanzania. Front Public Health, 2017; 5: 65.
5. George MS, Davey R, Mohanty I, Upton P. Everything is provided free, but they are still hesitant to access healthcare services: why does the indigenous community in Attapadi, Kerala continue to experience poor access to healthcare? Int J Equity Health, 2020; 19(1).
6. Gram L, Fitchett A, Ashraf A, Daruwalla N, Osrin D. Promoting women's and children's health through community groups in low-income and middle-income countries: a mixed-methods systematic review of mechanisms, enablers and barriers. BMJ Glob Health, 2019; 4(6): e001972.
7. Haddad S, Mohindra KS, Siekmans K, Màk G, Narayana D. Health divide between indigenous and non-indigenous populations in Kerala, India: population-based study. BMC Public Health, 2012; 12: 390.
8. Kaufman RE. Hematology: synthesis of sickle and normal hemoglobins: laboratory and clinical implications. Lab Med, 1999; 30(2): 129.
9. Keikelame MJ, Swartz L. Decolonising research methodologies: lessons from a qualitative research project, Cape Town, South Africa. Glob Health Action, 2019; 12(1): 1561175.
10. Colah R, Gorakshakar A, Nadkarni A. Hemoglobinopathies in tribal populations of India: prevalence, genetics, clinical management and research needs. *Indian J Med Res*, 2015; 141(5): 505–510.
11. Gopichandran V, Chetlapalli SK. Dimensions of social capital of families with thalassemia in an indigenous population in Tamil Nadu, India – a qualitative study. *Int J Equity Health*, 2017; 16: 54.
12. Nagar R, Sinha S, Raman R. Haemoglobinopathies in eastern Indian states: a demographic evaluation. *J Community Genet*, 2014; 6(1): 1–8.
13. Purohit A, Huda RK, Mohanty SS, Babu BV. Epidemiology of sickle cell disease in tribal population of Southern Rajasthan, India. *Sci Rep*, 2025; 15: 2196.
14. Desai C. Awake, Arise and Aware 3 make India Sickle Cell free: A supportive Initiative. *J of Pharm Sci bioscientific res*, 2015; *5*(2): 207-210.
15. Lagoo J, Lagoo A. The study of the incidence of pregnant women with sickle cell disease. Int J Reprod Contracept Obstet Gynecol, 2019; 8(10): 3950–4.
16. Loechl C, Datta-Mitra A, Fenlason L, Green R, Hackl L, Itzkowitz L, et al. Approaches to address the anemia challenge. J Nutr, 2023; 153.
17. Malyadri P. Income generation schemes for sustainable development of tribal women. Humanit Soc Sci Rev, 2020; 8(1): 634–42.
18. Paul K. Tribal health and development: some socio-cultural dimensions. Orient Anthropol, 2005; 5(2): 257.
19. Puri P, Pati S. exploring the linkages between non-communicable disease multimorbidity, health care utilization and expenditure among aboriginal older

adult population in India. Int J Public Health, 2022; 67: 1604333.
20. Safiri S, Kolahi A, Noori M, Nejadghaderi SA, Karamzad N, Bragazzi NL, et al. Burden of anemia and its underlying causes in 204 countries and territories, 1990–2019: results from the Global Burden of Disease Study 2019. J Hematol Oncol, 2021; 14(1): 185.
21. Sheath D, Castañeda RR de, Bempong NE, Raviǵlione M, Machalaba C, Pepper MS, et al. Precision global health: a roadmap for augmented action. J Public Health Emerg, 2020; 4: 5.
22. Stanley LR, Swaim RC, Kaholokula JK, Kelly K, Belcourt A, Allen J. The imperative for research to promote health equity in indigenous communities. Prev Sci, 2017; 21(Suppl 1): 13–22.
23. Swamy RN. An analysis of Sakshar Bharat in the context of tribal education. Indian J Public Adm, 2010; 56(3): 406–17.