International Journal of Community Medicine and Public Health
Nagisetty S et al. Int J Community Med Public Health. 2024 Nov;11(11):4537-4545
http://www.ijcmph.com
pISSN 2394-6032 | eISSN 2394-6040

DOI: https://dx.doi.org/10.18203/2394-6040.ijcmph20243320

Review Article

Sickle cell disease burden among tribal population of India: a narrative review

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Received: 01 October 2024
Revised: 16 October 2024
Accepted: 18 October 2024

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ABSTRACT

Sickle cell disease (SCD) is a serious health challenge for tribal communities in India. These groups often have limited access to healthcare, lack proper awareness of the disease, and face higher rates of illness and death due to SCD. This review looks at the impact of SCD on tribal populations and identifies the states where the burden is most significant. A review of existing literature was conducted using sources like PubMed and Google Scholar. The focus was on studies that explored the prevalence of SCD among tribal populations. Various government reports and research articles were also examined to create a well-rounded understanding of how SCD affects these communities. The findings show that Madhya Pradesh and Chhattisgarh have particularly high rates of SCD compared to other parts of India. In these states, between 10% and 30% of tribal groups carry the sickle cell trait. Other states, such as Odisha and Maharashtra, have lower rates of the disease, suggesting that specific attention is needed in regions like Madhya Pradesh and Chhattisgarh to manage the disease more effectively. SCD continues to pose a serious public health issue in India's tribal regions, particularly in certain states. It is essential to develop strategies that focus on raising awareness, improving access to healthcare, and managing SCD effectively in these communities. Public health efforts must include community involvement, education programs, and policy changes to better address the unique challenges faced by these populations.

Keywords: Sickle cell disease, Tribal health, Prevalence, Tribes

INTRODUCTION

Sickle cell disease (SCD) is a hereditary blood disorder characterised by abnormal haemoglobin structure, leading to distorted red blood cells with sickle- like shape or crescent shape.[1] These sickle cells are prone to blockages in blood vessels, causing episodes of severe pain, anemia and other complications that can be life- threatening.[2] SCD is particularly common among people with ancestral origins in regions such as Sub-Saharan Africa, India, Saudi Arabia, and Mediterranean countries.[3]

The World Health Organization (WHO) has acknowledged SCD as a significant global public health concern.[4] Between 2000 and 2021, the global prevalence of the disease increased by 41.4%, with the number of people affected growing from 5.46 million to 7.74 million.[5] India contributes to 14.5% of the worldwide burden of SCD. In 2010, it was estimated that 42,016 children were born with SCD, while 9,96,563 were born with sickle cell trait. According to the 2021 Global Burden of Disease (GBD) study, the all-age prevalence rate of SCD in India was 89.6 per 1,00,000 populations.[6]

SCD impacts populations globally but presents a particularly heavy burden on certain ethnic groups, especially among India's tribal communities, where the frequency of the sickle cell gene is notably high.

Tribes of India

The term "Tribe" is used in various contexts to describe a type of human social group. The word originates from the Latin term "Tribus" which in ancient Rome denoted administrative divisions and voting groups.[7] Tribals are commonly referred to by various terms such as Adivasi, Vanya Jati, Vanvasi, Pahari, Adimjati and Anusuchit Jati.[8] India is home to a significant tribal population, accounting for about 8.6% of the country's overall population.[9] Approximately 83% of India's Scheduled Tribe population resides in rural areas, predominantly concentrated in Madhya Pradesh, Maharashtra, Odisha, Gujarat, Rajasthan, Jharkhand, Chhattisgarh, Andhra Pradesh, West Bengal, and Karnataka.[10]

These indigenous groups, often known as scheduled tribes (STs), are distributed across various geographic regions and exhibit distinct cultural, social and genetic characteristics. Many of these tribes face unique health challenges, often exacerbated by limited access to healthcare, socio- economic constraints and geographic isolation. Among the health concerns disproportionately affecting tribal populations is SCD, a hereditary blood disorder that primarily affects individuals from certain ethnic and geographic backgrounds. SCD is especially common among various tribes in India, representing a significant public health issue due to its considerable rates of illness and death affecting approximately 1 in every 86 births.[11] The proportion of sickle cell carriers in different tribal communities varies between 1% and 40%. Madhya Pradesh bears the highest burden, with approximately 961,492 individuals identified as sickle cell heterozygotes and 67,861 as sickle cell homozygotes.[12]

This narrative review aims to highlight the prevalence of SCD among the tribes of India, emphasizing the urgent need for targeted public health interventions.

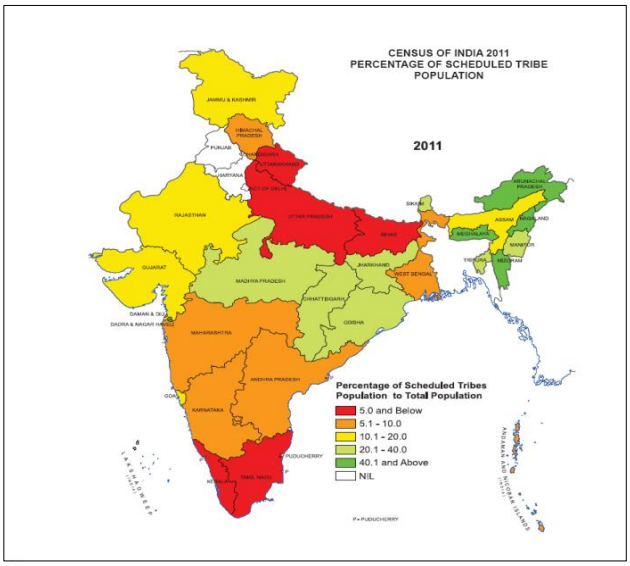

Figure 1: Distribution of tribal population in India: (source: Census of India 2011).[13]

METHODS

This narrative review focuses on the prevalence of SCD among tribal populations in India. A comprehensive search of the literature was conducted using the PubMed database, with search terms including sickle cell disease, sickle cell anemia, SCD, hemoglobinopathies, HbS, haemoglobin S, tribal population, tribes, indigenous population, scheduled tribes, and ethnic groups.

The search was limited to articles published between 2013 and 2024. To ensure a broader capture of relevant literature, a parallel search was performed on Google Scholar, applying the same terms.

Titles and abstracts of the identified articles were screened for eligibility. Articles were included if they specifically reported on SCD or related hemoglobinopathies in tribal or indigenous populations in India. Studies focusing on other geographical regions or unrelated to the tribal context were excluded. Duplicates were removed through cross-verification.

Articles lacking full-text access, those providing only abstracts, and editorials were excluded from the review. Studies included were analysed for their relevance to the burden, prevalence, and clinical manifestations of SCD in India's tribal populations. The reference sections of the chosen articles were thoroughly examined to uncover any additional relevant research.

STATE WISE DISTRIBUTION OF SCD AMONG TRIBES OF INDIA

Madhya Pradesh

It has the highest tribal population in India.[14]

Bhil

The Bhil tribe, recognized as one of the most significant tribal communities in India and Madhya Pradesh, is distributed across several districts within the state. The occurrence of SCD within the Bhil tribe in Madhya Pradesh varies between 15% and 33%.[15]

Gond

In a study conducted by Yadav et al among 776 patients from Jabalpur and surrounding districts of Madhya Pradesh, the prevalence of SCD in the Gond tribal community was reported to be 13.8%.[16] Additionally, Gupta's study indicated that the average prevalence of sickle haemoglobin in the Gond tribe is 15%, with some variation. Generally, the prevalence ranges between 15% and 25%, except in Chhindwara, where the Gond tribe exhibited a notably lower prevalence rate of 4%. Overall, the prevalence of SCD in the Gond tribe of Madhya Pradesh varies between 10% and 25%.[17]

Kol and Korku

In a retrospective and prospective survey conducted at GMC Shahdol from 2021 to 2023, Singh et al studied 600 patients with sickle cell anemia. The findings indicated a 7% prevalence of the disease within the Kol tribal community.[18] In contrast, Gupta reported a higher prevalence of 15% among the Korku tribes.[17] These data highlight the significant variation in the burden of SCD across different tribal populations in India.

Saharia

The Saharia tribe, recognized as a particularly vulnerable tribal group (PVTG) in Madhya Pradesh, was found to have a 0.97% prevalence of sickle cell anemia in a study by Urade et al.[19] However, previous research by Debnath and Chakma et al reported no presence of the sickle cell gene among the Saharia tribe, identifying only β-thalassemia.[20,21] These contrasting findings underscore differences in hemoglobinopathies within this tribal group over time.

Baiga

In Madhya Pradesh, the Baiga tribe is notably affected by SCD. According to a study conducted by Kumar et al the prevalence of the sickle cell trait in this community ranges between 10 to 15%.[22] Another study by Dawar et al reported a higher prevalence rate of SCD at 33% among the Baiga population.[23]

Bharia

In a study conducted by Chourasia et al in Madhya Pradesh, India, the prevalence of sickle cell trait among the Bharia tribe was reported to range between 10.7% and 15.6%, while the prevalence of SCD in this population was found to be between 0.4% and 0.8%.[24]

Panika and Pradhan

The study by Chourasia et al revealed that the allele frequency of the sickle cell gene was highest in the Pradhan tribe, followed by the Panika tribe.[24] According to research by Singh et al, the prevalence of sickle cell trait in these groups was reported at 28.6%.[25] Additionally, a study conducted by Kumar et al indicated that the prevalence of sickle cell trait in both the Panika and Pradhan tribes exceeds 20%.[22]

Chhattisgarh

A study by Patra et al indicates that the prevalence of SCD in India is greatest in the state of Chhattisgarh, where it reaches 23%.[26] According to a study by Lad et al the prevalence of the sickle cell gene is highest among the Gond, Halba, and Kanwar tribes. This finding comes from a large-scale population-based screening program conducted between 2007 and 2017 as part of the state sickle cell screening program in Chhattisgarh.[27]

Gond

The research conducted by Patra et al found that the prevalence of the sickle cell gene in the Gond community is 13%.[28] Furthermore, a study by Kumar et al reported that the prevalence of sickle cell disease in this population exceeds 20%.[22]

Halba

The research by Patra et al found that the prevalence of the sickle cell gene in the Halba community is 16%.[28] Additionally, another study by Kumar et al reported that the prevalence of sickle cell trait in this community exceeds 10%.[22]

Kanwar

In a study conducted by Urade, the prevalence of the sickle cell trait among the Kanwar tribe was found to be 3.3%.[29]

Muria and Hillmaria

Gupta's research identified the Muria and Hillmaria tribes of Bastar district as having the highest prevalence of sickle haemoglobin.[17]

Binjhwar

A study by Patra et al reported that the Binjhwar tribe of Chhattisgarh exhibited a sickle cell gene prevalence of 11%.[28] The findings from the study by Lad et al confirmed that the prevalence of the sickle cell gene was higher in the non-tribal population compared to the tribal population in Chhattisgarh, though the results varied across different groups.[27]

Maharashtra

A study by Colah et al revealed that several tribal groups in Maharashtra, including the Bhil's, Madias, Pawaras, Pardhans, and Otkars, exhibited a high prevalence of the sickle cell gene, ranging from 20% to 35%.[10]

Bhil

A study by Warade et al found that the prevalence of sickle cell trait among the Bhil tribe in Nandurbar district was notably high, at 20.6%.[30] These findings were further corroborated by Kate et al in their research on the epidemiology of SCD in Maharashtra.[31]

Madia

Colah et al reported that the prevalence of the sickle cell gene in the Madia community ranged from 20% to 35%.[10]

In a separate study, Kate found that the prevalence of SCD in this tribe was specifically 20%.[31]

Pawara

Warade et al conducted a study that revealed the prevalence of sickle cell trait to be 25.18% among the Pawara community.[30]

Pardhan

The Pardhan tribe of Maharashtra shows a high prevalence of the sickle cell gene.[32] A study by Urade et al conducted in central India reported that the Pradhan's of Yavatmal had a prevalence of SCD ranging from 16.8% to 33.7%.[29] In another study, Deshmukh et al found a prevalence of 10.6% in the same community.[33]

Otkar and Katkari

According to a study by Warade et al the prevalence of sickle cell trait was found to be 35% among the Otkar group in Gadchiroli district, marking the highest recorded prevalence in the study. Additionally, the Katkari group from Pune, Raigad, and Ratnagiri districts exhibited a prevalence of 5.90%.[30]

Varli and Malhar Koli

According to the National Institute for Research in Reproductive and Child Health (NIRRCH), the prevalence of SCD among these tribes in Maharashtra is reported to be 0.43%.[34]

In a study conducted by Deore et al the prevalence of SCD among urban parts of East Maharashtra was ranging between 0-14%.[35]

Studies from Maharashtra consistently indicate that the prevalence of Hb S is higher among the scheduled caste population, followed by the scheduled tribes.[15]

Gujarat

Dhodia, Dubla, Gamit and Naika

The study conducted by Saxena et al identified that the Dhodia, Dubla, Gamit, and Naika tribes exhibit a high prevalence of sickle haemoglobin (HbS), with rates ranging from 13% to 31%.[36] Additionally, Mistry et al found that among the tribal populations of the Valsad district, the Dhodia's represent the most affected community in terms of SCD. Dalal reported a prevalence of 18.4% for the sickle cell trait among the Dhodia tribe in the South Gujarat region.[37]

Chaudry, Rohit, Vasava and Kukana

Saxena et al reported a notably high prevalence of sickle haemoglobin (HbS), ranging from 6.3% to 22.7%, among various tribal groups in South Gujarat, including the Chaudry, Gamit, Rohit, Vasava, and Kukana communities. Additionally, the study indicated that the prevalence of sickle cell anemia was particularly high among the Vasava tribe (26.4%) and the Chaudhari tribe (21.4%).[36] Vasava et al reported that the majority (90%) of adolescents who tested positive for the sickle cell trait (83%) or disease (7%) belonged to the Vasava community.[38] Patel et al reported a 15.2% prevalence of the sickle cell trait within the Vasava tribal community. The study also identified that the Chaudry, Gamit, Vasava, and Rohit tribes are at high risk for both thalassemia and sickle cell anemia.[39]

Halpati

Mistry et al reported a 4.3% prevalence of SCD among the Halpati community in the Valsad district.[37] Rupani et al reported that the majority of school-going adolescents with sickle cell anemia belonged to the Vasava community, followed by the Chaudhari and Gamit communities.[40] Similarly, Sharma et al also found a high prevalence of sickle cell anemia among these groups.[41]

Orissa

Bhuyan and Khaira

Balgir's study revealed a high prevalence of haemoglobin variants among the Bhuyan (9.8%) and Kharia (13.3%) tribes, with SCD contributing 2.4% and 5.6%, respectively. Among the three Bhuyan subgroups, the sickle cell trait was found only in the Paraja (0.9%) and Paik (7.4%) subgroups, while no cases were detected in the Paudi (Hill) Bhuyan's.[42]

Kandha

Purohit et al reported a 9% prevalence of the sickle allele in the Kandha tribe of Odisha.[43] Sahu et al reported a 16.55% prevalence of SCD among children under fifteen years of age in the tribal areas of the Gajapati district, Orissa.[44] Das et al conducted a study in the Kandhamal district of Odisha and reported a high prevalence of SCD among the community studied.[45] Purohit et al reported a high prevalence of inherited haemoglobin disorders, such as the sickle gene, among the tribes of Western Odisha.[43] The sickle cell gene shows a high prevalence across various social groups, ranging from 0.3% to 20.7% in the general castes, 0% to 8.9% in the scheduled castes, and 0% to 5.5% in the scheduled tribes.[15]

Assam

Dunlop et al were the first to report the presence of HbS (sickle haemoglobin) among tea garden labourers in upper Assam.[46] Teli et al identified sickle cell anemia and β-thalassemia as major health concerns among the tribal populations working in the tea gardens of Assam.[47] These findings were further supported by Pathak et al.[48]

Table 1: Major tribal groups in different states of India.

States	Tribes
Madhya Pradesh	Bhil, Gond, Kol and Korku, Saharia, Baiga, Bharia, Panika and Pradhan
Chhattisgarh	Gond, Halba, Kanwar, Muria, Hillmaria, Binjhwar
Maharashtra	Bhil, Madia, Pawara, Pardhan, Otkar, Katkari, Varli, Malhar Koli
Gujarat	Dhodia, Dubla, Gamit, Naika, Chaudry, Rohit, Vasava, Kukana, Halpati
Orissa	Bhuyan, Khaira, Kandha
Manipur	Meitei, Naga
Rajasthan	Garasia, Bhil, Meena, Kathodi
Andhra Pradesh	Valmiki, Konda Kammara, Konda Dora, Konda Reddy, Thoti, Bagathas, Pardhan
Telangana	Banjara
Kerala	Adiya, Kuruma, Paniyas, Irula, Kurumba, Muduga
Karnataka	Jenukurubas, Koraga, Betta Kuruba, Beda, Yerava, Paniya, Eediga, Nayaka

Manipur

Shah et al reported that among males, the Meiteis exhibited the highest allele frequency of the sickle cell gene at 16.59%, while the Nagas had the lowest prevalence, at 8.6%.[49]

Arunachal Pradesh

Urade reported that the prevalence of the HbS gene in the Gallong tribe of Arunachal Pradesh was only 0.98%.[50]

Rajasthan

Garasia and Bhil

Mohanty et al reported a 9.54% prevalence of sickle cell anemia among the Garasia tribe residing in the Abu Road block of Rajasthan, while the Bhil tribe showed a prevalence of 2.41%. In a study conducted among tribal students in Maa-Baadi institutions in southern Rajasthan, he found the highest prevalence of SCD (13.81%) among the Garasia tribe.[51] Another study conducted by Mandot et al the prevalence of sickle cell anemia was observed to be 9.2% among the Garasia tribe.[52]

Meena and Kathodi

Mohanty et al reported that the occurrence of SCD in the Meena tribe was lower compared to the Garasia and Bhil tribes, with a prevalence of 3.25%. In contrast, the Kathodi tribe exhibited a higher prevalence, at 8.41%.[51]

Andhra Pradesh

Valmiki

A field survey carried out by Nayudu between 1978 and 1986 in the East Godavari district found a high incidence of the sickle cell gene among the Valmiki tribe, with a frequency of 31.5%.[53] Additionally, a study by Babu et al reported a prevalence of sickle cell disease at 15% in this tribal group.[54]

Konda Kammara

In a study conducted by Haritha et al among the Konda Kommaras in the Visakhapatnam district, the prevalence of the sickle cell trait was found to be 13.59%.[55]

Konda Dora

Haritha et al reported a prevalence of 7.8% for the sickle cell gene.[56] Another study by Devi et al found a sickling rate of 11.89% in the Konda Dora community.[57]

Konda Reddy

A field survey conducted by Nayudu reported the incidence of sickle cell disease in this group to be 13.4%.[53]

Thoti

Elizabeth et al conducted a study among the Thoti tribe in Adilabad district and reported that 12.84% of individuals were affected by sickle cell disease SCD.[58]

Bagathas

In a study by Haritha et al, 14.36% of individuals in the Bagatha community were found to be Sickler's.[56] Another study by Babu et al reported a sickling rate of 12.37% in this community.[59]

Pardhan

According to Feroze et al, 31.71% of sickling is present in this community.[60]

Telangana

Banjara

Ajmera et al in their study conducted among the Banjara community of Warangal district, reported a prevalence of 23.91% for sickle cell anemia.[61]

Kerala

Kuruma

In a study conducted by Feroze et al, the prevalence of sickle cell trait among the Kuruma community was reported to be 32.4%.[62] Similarly, Kaur et al observed a comparable frequency of 31.3%, further supporting these findings.[63]

Adiya, Paniya Irula, Kurumba and Muduga

Feroze et al reported a frequency of the HbS gene of 0.181 among the Adiya community and 0.095 among the Paniya community. In the Attappady region, the study also identified the sickle cell gene frequency across various communities, with Irula and Muduga both showing a frequency of 0.133, and Kurumba recording a frequency of 0.108.[60]

In the Wayanad district of Kerala, a total of 1,25,000 individuals from the tribal population were screened, and genetic counselling was provided, advising HbS carriers to avoid marrying other carriers.[64] The prevalence of HbS in these tribes was found to be notably high, ranging from 18.2% to 34.1%.[62]

Karnataka

In Karnataka, the prevalence of sickle cell disease among tribal populations is estimated at 4.05%, which is notably higher than the 0.84% prevalence observed in non-tribal populations.[65]

DISCUSSION

The present narrative review highlights the significant burden of SCD among tribal populations in India, with Madhya Pradesh and Chhattisgarh showing notably higher prevalence rates compared to other states.[65] This finding is consistent with previous reports, indicating that these regions are particularly affected due to the genetic predisposition of tribal communities and the lack of accessible healthcare infrastructure.[66] Such information is critical for public health planning and policy formulation, especially in designing targeted interventions for the most affected areas.

Our findings emphasize the urgent need for region-specific strategies to manage SCD. The high prevalence of the disease in tribal populations underscores the importance of expanding screening programs, improving genetic counselling, and ensuring better access to medical care in these underserved areas.[10] Given the hereditary nature of SCD, raising awareness and providing education on genetic transmission are also crucial in preventing the spread of the disease within these communities.[67] These aspects are particularly important for public health officials, healthcare providers, and policymakers working to reduce the health disparities faced by tribal populations in India.

The results of this review point to a gap in the availability of healthcare services in tribal areas, which often suffer from limited resources, making it challenging for individuals with SCD to receive timely diagnosis and treatment.[68] Strengthening the healthcare system, particularly in terms of capacity building, the availability of trained healthcare personnel, and access to diagnostic tools, is essential.[69] This will help to mitigate the severe health consequences of SCD in these populations and reduce associated morbidity and mortality.

However, this review is not without limitations. One key limitation is the reliance on data from existing literature, which may not comprehensively reflect the current situation in every tribal area. There is a lack of recent large-scale epidemiological studies focused on SCD prevalence in India's tribal communities, which limits the accuracy and generalizability of our findings. Furthermore, some regions may have been underrepresented in the literature, leading to potential bias in the conclusions. Another limitation is that the scope of the review does not cover the full range of interventions and management practices specific to tribal populations, as there is limited research on the effectiveness of different interventions in these contexts.

Further research is essential to better understand the full extent of the SCD burden in India, particularly through large-scale epidemiological studies that include underrepresented tribal regions. Additionally, more research is needed to evaluate the impact of current intervention programs and identify which approaches work best in these unique communities. Future studies should also focus on exploring the socio-cultural factors influencing healthcare access and the acceptability of interventions among tribal populations. Understanding these aspects will be key to designing culturally sensitive and effective healthcare strategies.

Addressing this public health challenge requires targeted interventions, improved healthcare infrastructure, and increased awareness efforts. While this review provides a valuable overview of the current situation, more research is needed to develop and implement effective, evidence-based solutions tailored to the needs of tribal communities.

CONCLUSION

SCD remains a significant public health challenge for tribal populations in India, characterized by considerable regional variations in prevalence. The high burden of SCD, particularly in Madhya Pradesh, Chhattisgarh, and Maharashtra, calls for immediate action from healthcare providers and policymakers. Moreover, areas typically not associated with SCD, such as Assam and Manipur, are now beginning to see an increase in cases among tea garden workers and other tribal groups, suggesting a need for

broader awareness and screening. Addressing this challenge requires a multifaceted approach that encompasses targeted genetic screening, the development of healthcare infrastructure, and culturally informed educational initiatives. Future research should aim to fill the existing gaps in prevalence data, explore the socio-cultural dimensions of the disease, and enhance clinical management strategies for these vulnerable communities.

Funding: No funding sources
Conflict of interest: None declared
Ethical approval: Not required

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Cite this article as: Nagisetty S, Thatoju PK. Sickle cell disease burden among tribal population of India: a narrative review. Int J Community Med Public Health 2024;11:4537-45.