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Sickled but Not Silent: Community Screening and Awareness of Sickle Cell Disorders among Tribal Adolescents in Nashik District, Maharashtra

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Abstract

Background: Sickle cell disease (SCD) and sickle cell trait (SCT) are critically prevalent inherited blood disorders, commonly affecting tribal population in India due to genetics and socio-cultural practices like endogamy. With limited available data, this study aimed to assess the prevalence of SCD and SCT among adolescents (12-16 years) and parental awareness. ***Materials and Methods:*** It was a cross-sectional study conducted among 2465 adolescents from 28 randomly selected tribal villages in Nashik district, Maharashtra with disease screening using solubility test, high performance liquid chromatography (HPLC) or Hb electrophoresis. Questionnaire based assessment of parental awareness was done. ***Results:*** A total of 2465 adolescents were screened using solubility tests, with positive cases confirmed through HPLC/HB Electrophoresis. Out of the screened adolescents, 114 (4.62%) were identified as carriers and 6 (0.24%) confirmed as SCD, resulting in a total prevalence of 4.87% for SCD-related hemoglobinopathies. An additional 171 adolescents (6.94%) were diagnosed with other hemoglobinopathies, including beta-thalassemia trait and HbD, raising the total hemoglobinopathy burden to 11.81%. Predominantly, 77.5% of the affected individuals were asymptomatic at the time of screening. Parental awareness assessment revealed that 60.6% had adequate knowledge (>50% correct responses), indicating improved understanding post-Information, Education, Communication interventions. Personalized counselling sessions and the use of color-coded health cards enabled community engagement and follow-up. ***Conclusion:*** This study highlights the hidden burden of hemoglobinopathies in tribal adolescents and brought out the need for integrated programs comprising routine screening, early diagnosis, genetic counselling, and community awareness to improve health outcomes and reduce disease-related complications.

Keywords: Anemia, Sickle Cell, Hemoglobinopathies, Adolescents, Indigenous Peoples, Mass Screening, Genetic Diseases, Inborn

INTRODUCTION

Sickle cell disease is a lifelong, debilitating public health problem impacting the quality of life. It is a monogenic inherited blood disorder (hemoglobinopathy) caused by changes in β globulin gene (HBB) resulting in formation of abnormal hemoglobin and red cells become stiff and sickle shaped.1,2 Blockage of blood capillaries restricts the blood flow and oxygen supply leading to development of chronic pain, severe anemia, infection, kidney and cardiovascular complications, high risk of infection, complications during pregnancy etc. Inheriting two hemoglobin S (HbS) genes causes sickle cell disease (SCD) while person with one HbS gene develops sickle cell trait (usually with no symptoms but can transmit the disease to next generation).[1,3]

According to the Global Burden of Disease Study (GBD) in 2021, nearly 7.7 million people worldwide had sickle cell disease and about 515,000 newborns were diagnosed with the disease. The global SCD birth rate was reported to be 382 per 100,000 live births. The global cause specific death and total deaths due to SCD were 34,400 and 376,000 respectively in the same year. Western and Central Sub-Saharan Africa and India reported highest SCD disability burden. India accounts for 82,500 newborns with SCD cases representing 16% of global incident cases while the total number of sickle cell disease across all ages was 1,280,000.[4]

According to 2011 Census, the tribal population (scheduled tribes) in India was around 104 million

constituting 8.6% of total population.5 The tribal population in Maharashtra state comprises of 10.5 million (~10%) of total tribal population of India. One of the districts in Maharashtra, Nashik hosts nearly 1.6 million tribal population estimating around 14.9% of total tribal population of Maharashtra.[6]

The sickle cell disease is a significant health concern in tribal population as they face vulnerability due to limited accessibility to healthcare facilities, low awareness and poor socio-economic conditions. It is also observed that SCD is prevalent among tribal population. The highest prevalence of sickle cell gene in some tribes of Maharashtra ranges from 20% to 35%.[7]

National Sickle Cell Anemia Elimination Mission by the Government of India was launched on July 1, 2023 which targeted on eliminating the disease by 2047. Around 60 million people have been screened out of targeted 70 million (aged 0-40 years) for the disease with around 0.2 million SCD cases and 1.67 million carriers and highest incidences were reported in the states of Odisha, Chhattisgarh, Madhya Pradesh, Maharashtra and Gujarat. The mission focuses on creating awareness, affordable and accessible services, counselling and holistic management for the disease.[8]

Early detection of sickle cell disease and sickle cell traits is important for reduction of death, preventing complications and improvement of quality of life. Screening in high risk populations helps in identifying the disease and that will enable timely supportive care, preventive treatment and counselling.9 The study was conducted among adolescents aged 12-16 years as this age group faces additional stress due to disease progression and it provides a critical window for early diagnosis, timely management and creating awareness to reduce stigma ultimately decreasing disease severity and burden.10 Therefore, the present study was conducted to assess prevalence, clinical symptoms and complications, evaluate community awareness and provide insights for planning early interventions and education programs. By focusing on a vulnerable and often neglected age group, this study will provide valuable insights that may help in understanding the epidemiology of SCD in tribal Maharashtra and may support clinical decision making and policy initiatives for early diagnosis and care.

MATERIALS AND METHODS

It was a cross sectional observational study conducted among adolescents 12-16 years of age in tribal villages of Nashik District, Maharashtra, India during July 2024 to June 2025. The study aimed to assess the prevalence of Sickle Cell Disease (SCD) and Sickle Cell Trait (SCT) among the study population along with associated factors and level of awareness.

The study area, Nashik had 15 administrative blocks, of which 9 were tribal blocks. According to data and reports from the National Sickle Cell Disease Control Programme provided by state health authorities, 7 tribal blocks with reported SCD were considered for study. Four (4) villages were selected from each of these blocks using simple random sampling leading to 28 villages for the study.

Adolescents both male and female aged 12-16 years of age, permanent residents of the selected villages and given written informed assent and parental/guardian consent were included in the study. The adolescents who had received blood transfusion within preceding 2 weeks of the study, already diagnosed with SCD/SCT, moved out of the village during the study and declined to participate were excluded from the study. Those already diagnosed with SCD/SCT were included for counselling and referral services, though not as part of the study.

All eligible adolescents in the selected villages were included in the study adopting total enumeration sampling. Total 2465 adolescents were surveyed and screened for the study. This was conducted in four structured phases such as line listing of all eligible adolescents in the selected villages, on site data and blood sample collection for screening of SCD/SCT followed by counselling and referrals along with community health education. Based on the findings and analysis, public health recommendations were made.

Approval from Institutional Ethics Committee (IEC) was obtained and all ethical guidelines were followed during the study period. The written informed assent from the participant and written informed consent from parents/legal guardians were obtained before participation in the study. Anonymity of the participants was ensured and no personal identifiers were collected.

After initial data collection about demographic factors and awareness parameters, initial screening was done using blood solubility test. This test was used as a first line screening test owing to its cost-effectiveness, immediate result, high sensitivity (93.8%) and specificity (100%).11 Positive samples were further subjected to high performance liquid chromatography (HPLC) or Hb electrophoresis for definitive diagnosis and differentiating between SCD, SCT and other hemoglobinopathies.

Structured proforma was used to collect demographic details, symptoms and detailed history. Standardized reporting formats as per state health department guidelines were used to enter laboratory results. Awareness of parents or guardians about SCD was assessed using self-administered questionnaire to understand the disease origin, transmission, symptoms, complications and preventive measures. The questionnaire was tested on 10% of the participants different from study group and finalized accordingly. Respondents were classified as aware if they correctly answered more than 50% of the questions and unaware if they scored less than 50%. Documentation about

Information, Education and Communication (IEC) activities, counselling sessions, community education and health cards was maintained.

The participants who were identified as carriers/diagnosed with SCD/SCT were subjected to personalized counselling along with their parents/guardians. Color coded cards-red for SCD, yellow for SCT and white for negative results were provided. The detailed guidance on preventive aspects was given including hydration, avoidance of cold and strenuous activity, infection prevention and necessary immunization.

Data were entered into Microsoft Excel and analyzed using SPSS version 25. Descriptive statistics such as frequencies, percentages and mean were used to describe demographic and clinical variables.

RESULTS

Out of total 2465 adolescents screened, 114 individuals (4.62%) were identified as carriers (HbAS) and 6 individuals (0.24%) were confirmed sufferers (HbSS), bringing the total prevalence of sickle-related hemoglobinopathies to 4.87%. Additionally, 171 adolescents (6.94%) were found to have other hemoglobin disorders such as β-thalassemia trait, α-thalassemia trait, HbD, and persistent fetal hemoglobin variants. The combined burden of hemoglobinopathies in this adolescent tribal population was found to be 11.81%. These findings indicate the possibly high genetic load of hemoglobin disorders in tribal areas of Nashik district.

A total of 120 out of 2465 adolescents were found to be either carriers or sufferers of sickle cell disease and trait with 57 (47.5%) males and 63 females (52.5%). (Figure 1)

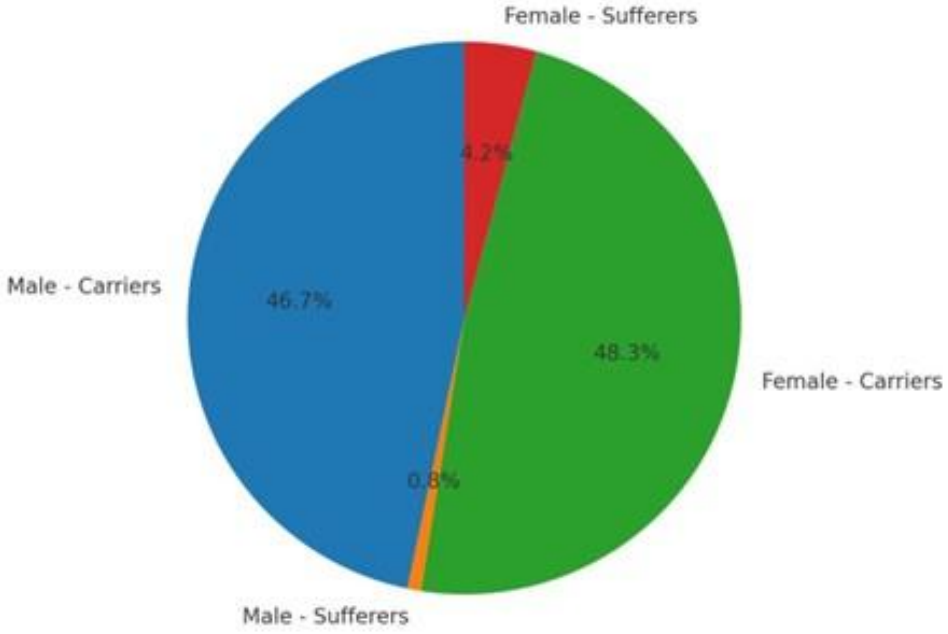

Figure 1: Distribution of Male and Female Carriers and Sufferers of Sickle Cell Disease and Trait

Notably, 93 (77.5%) adolescents were asymptomatic, highlighting the silent progression of SCD/SCT; followed by anemia (26;21.6%) and pain episodes (4;3.3%).

The caste wise distribution of carriers & sufferers showed predominance of caste Kokana (72;60%) followed by Mahadev Koli (21;17.5%), Warli (19;15.8%) and Bhil (8;6.6%).

Tables 1A, 1B and 1C depict the prevalence of sickle cell disease, sickle cell carriers and other hemoglobinopathies among adolescents across different blocks, PHCs and villages in Nashik district.

Table 1 A: Block/PHC/Village-wise Prevalence of Sickle Cell Disease, Carriers and Other Hemoglobinopathies Among Tribal Adolescents (Part I) Blocks: Baglan and Dindori

Block	Name of PHC	Name of Village	Actual no. 12-16 yrs population	No. of +ve samples	Village wise Incidence	No. of Sickle Cell Carriers	Carriers Incidence	No. of Sickle Cell Sufferers	Sufferers Incidence	No. of Other Hemoglobinopathies detected	Other Hemoglobinopathy Incidence
Baglan	Aliyabad	Jaad	96	8	8.33%	8	8.33%	0	0.00%	5	5.21%
		Bhimkhet	114	7	6.14%	6	5.26%	1	0.88%	8	7.02%
	Kelzar	Bundhate	123	4	3.25%	3	2.44%	1	0.81%	12	9.76%
		Tatani	91	4	4.40%	3	3.30%	1	1.10%	8	8.80%
	Block Total		424	23	5.42%	20	4.72%	3	0.70%	33	7.78%
Dindori	Nanashi	Palasvihir	152	4	2.63%	4	2.63%	0	0.00%	13	8.55%
		Mahaje	113	2	1.77%	2	1.77%	0	0.00%	10	8.85%
	Pandane	Ahiwantwadi	128	5	3.91%	5	3.91%	0	0.00%	10	7.81%
		Chausale	145	1	0.69%	1	0.69%	0	0.00%	9	6.21%
	Block Total		538	12	2.23%	12	2.23%	0	0.00%	42	7.81%

Table 1 B: Block/PHC/Village-wise Prevalence of Sickle Cell Disease, Carriers and Other Hemoglobinopathies Among Tribal Adolescents (Part II) Blocks: Igatpuri and Kalwan

Block	Name of PHC	Name of Village	Actual no. 12–16 yrs population	No. of +ve samples	Village wise Incidence	No. of Sickle Cell Carriers	Carriers Incidence	No. of Sickle Cell Sufferers	Sufferers Incidence	No. of Other Hemoglobinopathies detected	Other Hemoglobinopathy Incidence
Igatpuri	Kaluste	Kurungwadi	59	0	0.00 %	0	0.00 %	0	0.00 %	2	3.39%
		Shenwad Bk	100	0	0.00 %	0	0.00 %	0	0.00 %	6	6.00%
	Vaitarana	Walvihir	53	0	0.00 %	0	0.00 %	0	0.00 %	3	5.66%
		Pimpalgaon Bhatata	44	0	0.00 %	0	0.00 %	0	0.00 %	0	0.00%
	Block Total (Igatpuri)		256	0	0.00 %	0	0.00 %	0	0.00 %	11	4.30%
Kalwan	Dalwat	Virshet	63	2	3.17 %	2	3.17 %	0	0.00 %	5	7.94%
		Shingashi	46	2	4.35 %	2	4.35 %	0	0.00 %	2	4.35%
	Jaidar	Sule	47	3	6.38 %	3	6.38 %	0	0.00 %	4	8.51%
		Pratapnagar	108	6	5.56 %	6	5.56 %	0	0.00 %	11	10.19%
	Block Total		264	13	4.92 %	13	4.92 %	0	0.00 %	22	8.33%

Information, Education and Communication (IEC) activities were carried out in each selected village through 25 schools, 15 college seminars and 24 Gram Sabha sessions. Distribution of 2547 brochures and 2282 pamphlets, along with organization of 22 school rallies were conducted. Mass media and social platforms such as WhatsApp groups, community notice boards and loudspeaker announcements were also used to reach wider audiences. The goal was to educate adolescents, parents and village leaders about the nature, symptoms, complications and prevention of SCD. Notably, Pandane, Kelzar and Chinchohol villages showed highly active participation with multiple outreach formats.

Table 1 C: Block/PHC/Village-wise Prevalence of Sickle Cell Disease, Carriers and Other Hemoglobinopathies Among Tribal Adolescents (Part III) Blocks: Peth, Surgana and Trimbakeshwar

Block	Name of PHC	Name of Village	Actual no. 12–16 yrs population	No. of +ve samples	Village wise Incidence	No. of Sickle Cell Carriers	Carriers Incidence	No. of Sickle Cell Sufferers	Sufferers Incidence	No. of Other Hemoglobinopathies detected	Other Hemoglobinopathy Incidence
Peth	Kumbhale	Hatrundi	91	5	5.49 %	4	4.40 %	1	1.10 %	10	10.99%
		Dhondmal	94	12	12.77 %	11	11.70 %	1	1.06 %	9	9.57%
	Karanjali	Usthale	60	0	0.00 %	0	0.00 %	0	0.00 %	0	0.00%
		Borvat	62	0	0.00 %	0	0.00 %	0	0.00 %	2	3.23%
	Block Total (Peth)		307	17	5.54 %	15	4.89 %	2	0.65 %	21	6.84%
Surgana	Barhe	Thangaon	108	4	3.70 %	4	3.70 %	0	0.00 %	6	5.56%
		Bhegu	46	2	4.35 %	2	4.35 %	0	0.00 %	2	4.35%
	Bubli	Shribhuvan	85	3	3.53 %	3	3.53 %	0	0.00 %	8	9.41%
		Waghdhond	21	0	0.00 %	0	0.00 %	0	0.00 %	1	4.76%
	Block Total (Surgana)		260	9	3.46 %	9	3.46 %	0	0.00 %	17	6.54%
Trimbakeshwar	Chinchohol	Deodongara	107	7	6.54 %	7	6.54 %	0	0.00 %	6	5.61%
		Goldari	116	15	12.93 %	14	12.07 %	1	0.86 %	2	1.72%
	Thanapada	Kharshet	80	4	5.00 %	4	5.00 %	0	0.00 %	6	7.50%
		Dalpatpur	113	9	7.96 %	9	7.96 %	0	0.00 %	3	2.65%
	Block Total (Trimbakeshwar)		416	35	8.41 %	34	8.17 %	1	0.24 %	17	4.09%
Total Block			**2465**	**120**	**4.87 %**	**114**	**4.62 %**	**6**	**0.24 %**	**171**	**6.94%**

Table 2: Awareness of Sickle Cell Disease (SCD) and Sickle Cell Trait (SCT) Among Parents/Guardians Across Tribal Villages (N=2465)

Sr No	Block	PHC	No. of Villages	No. of Parents / People Surveyed	Aware of Sickle Cell Disease (>50% correct answers)	Not Aware (<50% correct answers)
1	Baglan	Aliyabad	2	210	48%	52%
		Kelzar	2	214	51%	49%
2	Dindori	Nanashi	2	265	60%	40%
		Pandane	2	273	65%	35%
3	Igatpuri	Kaluste	2	159	65%	35%
		Vaitarana	2	97	60%	40%
4	Kalwan	Dalwat	2	109	60%	40%
		Jaidar	2	155	65%	35%
5	Peth	Kumbhale	2	185	60%	40%
		Karanjali	2	122	61%	39%
6	Surgana	Barhe	2	154	62%	38%
		Bubli	2	106	65%	35%
7	Trimbak	Chinchohol	2	223	65%	35%
		Thanapada	2	193	62%	38%
Total District	—	—	**28**	**2465**	**60.64%**	**39.36%**

Out of 2465 respondents,1495 (60.64%) were aware about the sickle cell disease while remaining 970 (39.36%) gave less than 50% answer showing limited knowledge. (Table 2)

A key component of this study was to ensure that adolescents diagnosed as either carriers or sufferers of SCD received post-diagnostic counseling. This was crucial for disease understanding, precautionary practices and access to follow-up care.

DISCUSSION

In present study, total 2465 adolescents aged 12-16 years were screened from 28 tribal villages of Nashik district. The overall prevalence of sickle related hemoglobinopathies was found to be 4.87% (120 out of 2465) out of which 114 (4.62%) were identified as carriers (HBAS) and 6 (0.24%) were sufferers. Additionally, 171 (6.94%) adolescents had other hemoglobin related disorders thus the total hemoglobinopathies account for 11.81%. Around 93 (77.5%) adolescents with sickle related hemoglobinopathies were asymptomatic at the time of screening.

A systematic review and meta-analysis of Indian studies showed that national prevalence of sickle cell trait was 5.9% and sickle cell disease was 1.17%. Contrary to the present findings the prevalence of SCT and SCD in the state of Maharashtra was reported to be 14.48% and 2.06%.12 In another study by Colah et al showed that the prevalence for SCT ranges from 0% to 35%. These findings were comparatively higher than the present study.13 However, the SCD prevalence observed in present study aligned with finding (0.8%) of a systematic review and meta-analysis conducted among adolescents.14 The prevalence of present study was on the lower side of the reported range, this may be attributed due to differences in tribal composition, age group used in study, local environmental and social conditions.[12]

There were more females who were carriers and sufferers compared to males in present study. Similar observations were seen in other studies.[15,16]

The overall prevalence of 11.81% of all hemoglobinopathies was found to be in 291 adolescents. Findings from other studies by Mohanty et al.17 and Ganesh et al.18 reported prevalence ranging from 8.7% to 14.7% which nearly aligned with the present study.

In present study, the sickle carriers and sufferers were highest in Kokana tribe (60%) followed by Mahadev Koli, Warli and Bhil. Contrast to present study, the sickle cell hemoglobinopathies were most commonly seen in Bhil, Madia, Pawara, Pardhan and Otkar in study by Nagisetty S et al.7 The systematic review and meta-analysis showed that prevalence of SCD and SCT was more marginalized tribal communities compared to non-tribal population.[14]

Among carriers and sufferers most of the adolescents were asymptomatic (77.5%) followed by signs of anemia and pain. In a study, nearly 87% SCT patients were asymptomatic, only 13% had symptoms including anemia, hemolytic crisis and pain which was consistent with present finding. As SCT and SCD are inherited blood disorders, mostly symptomless. The disease is transmitted from parents to their children may sometimes lead to severe complications including death.19 Contrasting finding was reported in a study where the children with SCD were admitted to the hospital due to severe pain, infection and acute chest syndrome.[20]

Nearly two third parents or guardians of adolescents were aware about SCD in present study. Similarly, Das et al. found that around 74% participants were aware about the disease.21 However, another study reported only 32% awareness level showing marked difference between findings.22 The variation between studies may be due to differences in study location, population, literacy levels and health education and awareness programs.

The IEC activities and counselling using color coded cards was an innovative idea conducted to improve the awareness regarding disease, timely screening and reduction of stigma among people. This aligns with the goals of the National Sickle Cell Anemia Elimination Mission which emphasizes on screening and counselling.

Limited generalizability due to cross-sectional design and focus on few tribal communities as these might not represent the diverse genetic and socio-economic backgrounds of other tribal communities. However, the study provided an important insight into the prevalence of sickle cell disease and related hemoglobinopathies while also creating awareness and need for screening to help prevent future complications. This study will help by identifying high risk communities and may guide in designing specific programs like systematic screening using HPLC/electrophoresis in tribal schools and communities and providing a baseline for future longitudinal research to study long term impact as well as allocating dedicated resources for SCD.

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