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Original Research Article

Sickle cell disease in Sundargarh: understanding local beliefs and screening efforts among tribal population, Western Odisha

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ABSTRACT

Background: Sickle cell disease remains a significant health challenge among Odisha's tribal communities, where limited awareness and healthcare access lead to delayed diagnoses. This study examined the incidence of sickle cell disease and local perceptions of it in Sundargarh's Subdega and Balisankara blocks.
Methods: This cross-sectional study, conducted from June 2023 to March 2024 in Sundargarh, Odisha, examined the prevalence of sickle cell disease and assessed community perceptions using questionnaires, screenings, and HPLC analysis. 280 respondents participated, providing insights into sickle cell disease awareness, while 210 children were screened for early detection. Findings were presented through descriptive statistics, Pearson correlation, and Kruskal-Wallis tests, with significance set at $p<0.05$.
Results: A total of 280 adults (males: 117 and females: 163) with 95 children (below 15 years) from the same families were freshly diagnosed with sickle cell disease, and they were unaware of the condition. Of the 280 people sampled, 54.3% had not even heard of sickle cell disease; only 9.37% knew it was an inherited disease. Limited awareness of sickle cell disease led to misconceptions, with many relying on traditional healers.
Conclusions: The study found a prevalence of sickle cell anemia (HbSS) among variants of sickle cell disease, with limited awareness and testing. Strengthening education and healthcare access is essential for better detection and support, though overall perceptions of the disease were positive.

Keywords: Odisha, Perception, Sickle cell anemia, Sickle cell trait, Sundargarh, Tribal communities

INTRODUCTION

Within India, 73% of people carrying those genes belong to indigenous tribes residing in isolated areas.[1] Odisha is the homeland of 62 tribal communities, accounting for 9.2% of the country's tribal population, and the majority of these tribes live in districts like Kandhamal, Koraput, and Sundargarh.[2] Sickle cell disease (SCD) prevalence in India varies widely, with the highest rates in central regions; in Odisha, over 5.35 lakh people are affected, mostly in 13 western districts.[3] The tribal health expert committee report from the Ministry of Health and Family Welfare has highlighted SCD as one of the top ten specific issues affecting tribal communities.[4] Orissa is categorized as a high-prevalence zone with 21-40%.[5] Sundargarh has the highest number of cases at 3007, with Kandhamal following at 2109 cases.[6]

Sickle cell syndrome encompasses various genetic haemoglobin abnormalities, with sickle cell anemia being one type where red blood cells become sickle-shaped, leading to chronic anemia.[7] The sickle cell eradication program aims to address sickle cell disease prevalence in 17 states, with a focus on Odisha, where 20 districts, including Sundargarh, will benefit from the initiative.[5,8]

Despite the high prevalence of SCD in Odisha, many tribal communities remain unaware of the condition due to a lack of knowledge, awareness programs, and limited access to public health services, resulting in delayed or missed diagnosis of SCD and its various forms. Sundargarh, with its underdeveloped status and significant tribal population, along with the limited research conducted in this area; therefore, has been selected for the present study. Despite the policies being made, a few people know about it and do not understand the condition and its impact. The objective of this study was to identify the areas with the prevalence of SCD and to understand the knowledge and perceptions among tribal communities of the Subdega and Balisankara blocks of Sundargarh District. Through screenings and assessing local perceptions and knowledge, the study seought to facilitate early detection of SCD among these communities. This includes connecting individuals diagnosed with SCD to hospitals and health workers for further assessment and care. This approach is expected to improve health outcomes, empower individuals to make informed health decisions, and support the aspect of the SCD eradication mission.

METHODS

Study design

This study utilized a cross-sectional approach, carried out between June 2023 and March 2024. Data was collected using a self-structured questionnaire comprising three parts: the first part focused on demographic information, the second part on screening for SCD by sickling test, and (CBC) complete blood count.[9] The high-performance liquid chromatography (HPLC) method has been adopted to diagnose and identify specific variants.[10,11] The last part focused on knowledge and perception toward SCD through a personal interview. The questionnaires were translated into Sadri, and most interviews were conducted in Sadri and Sundargarhi languages. Data collection was carried out by self-administered interviews, and the screening team consisted of a doctor and two laboratory technicians. The study was conducted in six villages spanning two blocks within the Sundargarh district of Odisha. The selected villages were Subdega, Lathdega, Karamdihi, Balisankara, Tumulia, and Talsara. Before recruitment, informed written consent, translated into the local language (Sadri), was obtained from each participant during data collection.

130 households (65 per block) in Sundargarh district were surveyed, with 280 respondents assessing knowledge and perception towards SCD. Household members above 15 years who were willing to participate provided insights into their understanding of the condition, while 210 children (ages 1-15) from the same families underwent screening for early detection of SCD but were excluded from awareness-related analysis. Written consent for blood tests and sample collection was obtained from parents. Within these households, 210 children were screened to evaluate new incidence cases for early detection.

Approval was granted by the science faculty ethics committee at Banaras Hindu University (registered under CDSCO) on 06.05.2023. Additionally, ethical clearance was obtained from the Directorate of Health Services, Odisha, along with permission from the CDMO of Sundargarh to conduct research in the villages on 12 May 2023.

Analytical methods

The blood collection was supervised by a doctor and was carried out by lab technicians under sterile conditions. A 2 ml blood sample was drawn from the arm vein and collected in an ethylenediaminetetraacetic acid (EDTA) tube to prevent clotting. A reagent was prepared by mixing 0.2 grams of Sodium metabisulfite with 10 ml of distilled water. To ascertain sickle cell anemia, a mixture of one drop of blood and five drops of this reagent was prepared on a microscope slide. A cover slip was then placed and sealed with petroleum jelly, after which it was left for observation for 6-12 hours to detect any sickling. Moreover, a complete blood cell count analysis was conducted using an automated hematology analyzer (SYSMEX XN-1000). This analysis determines the level of red blood cells, providing insight into whether the individual has anemia. HPLC is a valuable tool for distinguishing between sickle cell anemia (SCA) and sickle cell trait (SCT). It works by separating different hemoglobin variants based on their retention times in a chromatographic column.

Table I: Hemoglobinopathies were identified using specific HPLC pattern criteria, enabling accurate classification and differentiation of haemoglobin variants.[12,13]

Conditions	HbA	HbS	HbF	HbA2	Hb (gm/dl)	MCHC (gm/dl)	MCH (pg)	MCV (fL)
Normal	96 -98%	0%	<2%	2-4%	12	32-36	27-33	80-90
HbSS	Absent or <10%	>50%	>5%	<5%	<12	Elevated	Reduced	Normal/increased
HbAS	56-60%	30-40%	<1%	<4%	11-12	Normal	Normal	Normal

Chronic anemia plays a crucial role in diagnosing SCA. It is characterized by a low or absent HbA, with an elevated percentage of HbS and HbF. The mean corpuscular volume (MCV) and mean corpuscular hemoglobin concentration (MCHC) tend to be higher, whereas red blood cell (RBC) count and overall hemoglobin levels are lower. In contrast, individuals with sickle cell trait exhibit a normal percentage of HbA alongside elevated levels of HbS, with HbA2 and HbF remaining within the normal range. Their red blood cell indices and hemoglobin levels generally fall within standard physiological parameters.

Sample and sampling method

Convenience sampling was employed for this study. The Daniel formula was used to calculate the sample size, based on a population prevalence of 25.5% from a pilot study conducted in one village (other than the selected one) of these blocks, which was further excluded from the main sample of the study.[14,15] A 95% confidence level and a precision of 0.05% were utilized in the calculation. Furthermore, individuals aged above 15 and from various communities were included, provided they gave consent.

Where n is the sample size, Z is the level of confidence, P is the expected prevalence, and d is the precision. Z (value at 95%) =1.96, P=22% =0.22, and d=0.05.

Daniel's formula was used for a prevalence-based study:

$$n = \frac{Z^2 P(1-P)}{d^2}$$

$$n = \frac{0.952 \times 0.22(1-0.22)}{0.052}$$

$$n = \frac{00.65921}{0.0025}$$

n= 263.68 taken as 264 (approx.)

It should be noted that although the original sample size was set at 264, apart from these 16, more participants were included in the survey as they were members of these respondents' families. Thus, the final sample size consisted of 280 participants, excluding children under 15 years from the family. This ensured that the study focused on respondents who could provide insights into the knowledge and perception of sickle cell anemia.

Data analysis

The collected data were carefully reviewed for completeness and then organized using MS Excel (version 16) before being transferred to SPSS (version 20, IBM Inc.) for analysis.

Descriptive statistics and the Pearson correlation coefficient were used to test the relationship between variables. Screening for SCD was presented using mean ± standard error to ensure precise estimates. One-sample t-test and analysis of variance were used among the variables assessed. These methods provided a rigorous statistical evaluation of variations in hemoglobin patterns and red blood cell indices. The data presentation represented the categorical variables using frequencies and percentages. In this study, the questions related to knowledge about SCD were measured on an ordinal scale. The knowledge scores were categorized as follows: "good" knowledge was represented by the first option, "fair" knowledge by the second, and "poor" knowledge by the last option. Responses like "don't know" and "can't say" were classified as signs of insufficient knowledge in the survey. In questions where the options were binary, such as "yes" or "no", only "good" and "poor" knowledge levels were assessed, with "good" corresponding to a positive response (e.g., "yes") and "poor" to a negative response (e.g., "no"). This approach allowed for a simplified categorization of knowledge levels concerning SCA. The independent-samples Kruskal-Wallis test and p value were used to analyze the knowledge and perception of SCD among respondents based on their education. P value <0.05 was statistically significant. The study findings were ultimately presented through tables, figures, and textual explanations

RESULTS

A total of 280 respondents were surveyed across six villages in Sundargarh district, with the majority of female respondents (58%) giving their consent to participate out of curiosity, surpassing the participation rate of male respondents. The average age of respondents was approximately 33.5 years, placing them primarily in the 25–35 years range, followed by the 15–25 years group. Table 2 indicates that a substantial portion of the population, representing 35.5%, does not have formal education. Awareness of sickle cell status was low, with only 45.7% knowing their status.

Table 3 reveals a significant variation in health worker visits across the surveyed villages in Sundargarh district. Lathdega and Talsara received visits fairly regularly, twice a year. In contrast, 36.78% of respondents reported that health workers were not visiting their villages at all, with Tumulia and Sapdagar having no outreach at all.

Among the 210 children aged 1 to 15 years (mean age 6.69±3.94), the group consisted of 98 males (46.8%) and 112 females (53.2%). The HbSS group showed significantly lower HbA levels (2.89±0.46%), markedly elevated HbS (86.4±1.0%), and increased HbF (7.3±0.25%), along with reduced hemoglobin concentration (8.32±0.21 gm/dl) and RBC count (3.98±0.11 $\times 10^6$/µl). In contrast, HbAS individuals maintained near-normal hemoglobin levels (11.27±0.18 gm/dl), with HbA at 60.87±0.91% and HbS at 40.31±0.71%, confirming the presence of the trait.

Table 2: Demographic characteristics of the respondents.

Characteristics	Frequency	Percentage
Distribution of respondents of the two blocks		
Subdega	131	46.79
Balisankara	149	53.21
Gender		
Male	117	42
Female	163	58
Age (years)		
15-25	66	23.6
25-35	110	39.3
35-45	51	18.2
45-55	41	14.6
>55 or above	12	4.3
Educational qualification		
Graduation	20	7.1
Up to secondary class	34	12.1
Up to the primary class	90	32.1
Up to three class	37	13.2
No formal schooling	99	35.5
Marital status		
Unmarried	64	22.8
Married	199	71.1
Widower	8	2.9
Widow	9	3.2
Number of children		
Only child	59	21.1
More than two children	151	53.9
No child	70	25.0
Knew their sickle cell status		
Yes	128	45.7
No	141	50.4
Can't recall if they have ever been tested	11	3.9

Table 3: Number of health workers visiting these villages.

Health Workers visiting to Villages	Frequency of the respondents (n)					
	Karamdihi	Lathdega	Sapdagar	Subdega	Talsara	Tumulia
At least once a month	0	0	0	5	0	0
At least once in three months	20	2	0	4	0	0
Twice in a year	0	32	0	0	58	0
Once a year	0	1	15	29	0	0
Don't know	0	10	0	1	0	0
Not visiting	3	4	29	20	8	39
Total	23	49	44	59	66	39

Table 5 reveals that anemia is the most strongly associated disorder with sickle cell disease (SCD), affecting 17.1% of respondents and showing a high correlation coefficient (r=0.71). Additionally, renal stone problems were reported in 14.1% of cases, with a similarly strong correlation (r=0.69).

Unfortunately, Table 6 indicates that a majority of respondents (54.3%) had never heard of sickle cell disease (SCD). Notably, it showed that affected individuals, friends, and relatives played a significant role in disseminating information about SCD. Among those who were aware, the most commonly believed cause was black magic (44.55%), while only 9.37% correctly identified it as an inherited condition. Regarding diagnosis, blood tests were the most recognized method (22.6%). When asked about prevention, 56.2% of respondents reported having no knowledge of any preventive measures.

Table 4: Comparison of hemoglobin patterns and RBC indices in SCA and SCT among children.

Variants	Normal	HbSS (SCA)	HbAS (SCT)
HbA (%)	96-98	2.89±0.46[a]	60.87±0.91[b]
HbS (%)	0	86.4±1.0[a]	40.31±0.71[b]
HbF (%)	<2	7.3±0.25[a]	4.55±0.39[b]
HbA2 (%)	2-4	2.5±0.1	2.09±0.14
Hb (gm/dl)	12-14	8.32±0.21[a]	11.27±0.18
MCHC (gm/dl)	32-36	35.02±0.38	33.61±0.5
MCH (pg)	27-33	24.6±0.44[a]	29.56±0.42
MCV (fl)	80-90	84.63±0.98	82.98±1.28
RBC count (×10⁶/µl)	4.5- 5	3.98±0.11[a]	4.8±0.12

a: P value <0.01 is statistically significant at 99% confidence level compared to normal.
b: P value <0.01 is statistically significant at 99% confidence level compared to normal.

Table 5: Other disorders associated with SCD.

Disorders	Frequency	Percentage	r (correlation coefficient)
Anemia	48	17.1	0.71
Renal stone problem	39	14.1	0.69
Other non-communicable disease	30	10.7	0.56
Hepatosplenomegaly	9	3.2	0.19
Gall bladder stone problem	5	1.8	0.13
Ulcers	6	2.1	0.15
Don't know	36	12.8	0.53
No other chronic disorder	107	38.2	0.18

Table 6: Knowledge regarding SCD among respondents.

Knowledge-related questions	n=280	%	P value
Ever heard of SCD			
Yes	128	45.7	0.006*
No	152	54.3	
Source of information	n=128		
Affected people families	35	12.5	
Friends and relatives	32	11.4	
Health workers	28	10	0.141
Mass media	21	7.5	
Other sources	12	4.3	
Causes of SCD			
Inherited	12	9.37	
Acquired	36	28.12	0.007*
By God's curse or past life sin	23	17.96	
Black Magic	57	44.55	
Method to diagnose SCD			
By blood test	29	22.6	
Both blood and urine tests	24	18.9	
By urine test	5	3.9	0.007*
Ultrasound and x-ray	6	5	
Superstitious belief	34	26.4	
Don't know	30	23.2	
Prevention measures to be taken			
All the measures (screening, avoiding marriage with an affected person, and premarital counselling)	12	9.6	
Screening and Avoiding marriage with an affected person	38	29.6	
No marriage between relatives	17	13.2	0.051*
Premarital counselling	4	3.2	
Don't know about the prevention	56	56.2	

*P value represents that there was a statistically significant difference at a 95% confidence level.

Table 7: Perception towards SCD.

Questions	Male (n= 117) (%)	Female (n=163) (%)	P value
Knew their child would be affected			
Yes	35	20	0.024*
No	24	34.4	
Uncertain	41	45.6	
Understanding the term SCD			
Yes	21.6	22.69	0.001*
No	78.3	77.3	
Considering marriage, knowing their partner's genotype			
Yes	11.9	7.9	0.037*
No	80	78.7	
Can't say	8.1	13.4	
Considering working directly with someone who has SCD			
Yes	43.5	34.3	0.061
No	32.4	36.9	
Hesitation/ can't say	24.1	28.8	
Organizing premarital counseling			
Yes	59.8	57.6	0.023*
No	24.7	26.5	
May be	15.5	15.9	
Encouraging others to go for screening for SCD			
Yes	72.6	74.2	0.110
No	20.5	21.4	
Uncertain	6.9	4.4	
Did you know about any policies or programs started by the government?			
Yes	19.6	6.7	0.005*
No	80.4	93.3	
Contact if diagnosed			
Doctors	51.2	44.3	0.018*
Village elders/spiritual healers	19.6	29.4	
Health workers	11.9	11.6	
Don't disclose	17.3%	14.7	

*: P value <0.05 is statistically significant at 95% confidence level.

The key findings from Table 7 show statistically significant gender differences in perception towards sickle cell disease (SCD). More males (35%) than females (20%) knew their child could be affected (p=0.024). When considering marriage, 11.9% of males and 7.9% of females were aware of the importance of knowing their partner's genotype. A majority of both genders supported organizing premarital counseling. Awareness of government programs was notably higher among males (19.6%) compared to females (6.7%), and more males (51.2%) preferred contacting doctors upon diagnosis than females (44.3%).

DISCUSSION

Sickle cell hemoglobinopathies are inherited disorders caused by mutations in the β-globin gene. These mutations lead to the production of abnormal hemoglobin S (HbS). This group includes several genotypes, such as HbSS, HbSC, HbS/β^0-thalassemia, HbS/β^+-thalassemia, and HbAS.[16] Sickle cell anemia (SCA) occurs when a child inherits the sickle gene from both parents (HbSS). Sickle cell trait (SCT) occurs when the gene comes from only one parent (HbAS).[17,18] The National Sickle Cell Anemia Elimination Mission, launched in the Union Budget 2023, aims to eliminate SCD by 2047 through early detection, prevention, and care for those affected, especially among tribal populations.[4] Given the high disease burden, it is also crucial to focus on spreading awareness regarding the knowledge of cause and prevention among people to ensure the mission's success.

In the present study, the distribution of respondents from six villages across two blocks in Sundargarh district where a total of 280 individuals were sampled. The respondents from Subdega block were drawn from the villages of Karamdihi, Lathdega, and Subdega. Additionally, the Balisankara block included participants from the villages of Tumulia, Sapdagar, and Talsara. 210 children (1-15 years) from the same household have been

surveyed. All the children underwent screening for sickle cell hemoglobinopathies, in which 95 children were found to either carry the trait or have SCA. Based on HPLC and RBC indices, 46 (48.4%) were identified as homozygous for sickle cell anemia (HbSS) and 49 (51.6%) as carriers of sickle cell trait (HbAS). Hemoglobin concentration (Hb 8.32±0.21 gm/dl) was significantly reduced, contributing to anemia. MCH (24.6±0.44 pg) and RBC count (3.98±0.11 $\times 10^6/\mu l$) were also markedly lower, further supporting the presence of chronic anemia. The observed differences in hemoglobin distribution and RBC indices underscore the distinct hematological profiles of SCA and SCT. The main finding of the study was that the prevalence of SCT (HbAS) was around 23% and SCA (HbSS) was 22% and can be supported by the same study done in various tribal groups in India.[19,20] The prevalence has been calculated from 210 screened children. The rate of sickle cell anemia in children was 16.5% in southern Odisha and 11.5% in western Odisha. Among the various haemoglobin disorders in the state, the sickle cell trait was reported at 29.8%, while sickle cell disease made up 7.6%.[21] Most respondents cited the inaccessibility of nearby schools or the lack of teachers as the main reasons for the lack of formal and quality education in this study. This supports the ongoing challenges in tribal education, such as infrastructure gaps, teacher shortages, and poor post-secondary transition support.[22] Disparities in health worker visits across villages can be seen in Table 3. Despite the government's extensive efforts to implement health programs in tribal communities, inconsistencies and absenteeism in health worker visits reveal significant shortcomings in rural healthcare, further intensified by geographic isolation and poor connectivity can be related to a similar study conducted.[23]

With over half (54.3%) of the respondents having never heard of the condition, it highlights a critical gap in public health education and late diagnosis, especially in the region where it is prevalent. It also highlights a significant gap in knowledge and screening, aligning with trends observed in similar studies.[3,24] On the contrary, a study conducted among the tribal people in the Kandhamal district in Odisha, where 74.2% of individuals reported having heard of the disease, and 69% were aware of modern treatment options.[25] The limited awareness in this study was attributed to inadequate outreach programs or campaigns. The parents' low literacy levels, lack of perceived importance, and inability to understand the heritable nature of the condition are the major causes. Almost all mothers think that these traits cannot be passed to their children, or some believe that they will eventually disappear over the years.

Rather than acknowledging its medical or genetic roots, the findings showed that many people blame SCD on supernatural factors such as black magic and punishment from their previous life.[26] Similarly, when it comes to diagnosis, a significant number rely on superstitious beliefs or admit uncertainty, showing limited awareness of scientific methods like blood and urine tests.

Since the majority of them had not even heard of SCD (Table 6), it is obvious that they did not understand the meaning of these disorders (Table 7). When traditional healers were asked about SCD and SCA, they also had no idea about it, were confused, and explained it as nutritional anemia. This result can be seen in a similar study.[27] This study showed a positive perception emerged regarding working with someone with SCD, willing to work alongside them, while rejected, and mostly women were hesitant to work with the person with SCD. The majority of respondents believe premarital screening is important after being made to understand the term (pre-marital counselling). It leads to many respondents expressing their willingness to encourage others to go for screening, as seen in a similar study in the Nabrangpur district of Odisha.[28] Most respondents said they would contact doctors for help with SCD, while some preferred village elders or spiritual healers. A few mentioned NGOs, Anganwadi workers, or ANMs as sources of support.

The limitations of the study were the small sample size with a fixed timeframe, and the challenges in building rapport with these communities. Limited literacy rates and infrequent health worker visits were barriers.

CONCLUSION

The study identified a notable occurrence of HbSS and HbAS in equal proportions among variants of sickle cell disease. It was found that more females (25.7%) were affected than males (19.5%). After screening, their parents have been informed about their children's condition, and the data about the children identified as SCD was given to the Anganwadi workers, who connected them to the district hospital. Despite the high occurrence of SCD, awareness and testing remain low, with only 45.7% of respondents being aware of their status. The study emphasized the need for genetic counselling, pre-marital counselling, and increased healthcare access. Recommendations include continued research, targeted education, and community collaboration to raise awareness and combat myths. Forming village groups to spread awareness and educate both genders can yield positive outcome.

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