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Knowledge, Attitude, and Practice regarding Sickle Cell Disease among Screened Adults in the Tribal Village of Jashpur: A Cross-Sectional Study

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Abstract: ***Background: Sickle cell disease (SCD), a hereditary hemoglobinopathy, remains a significant public health concern in tribal communities of Chhattisgarh, India. Despite governmental screening programs, poor knowledge and awareness persist. This study aimed to assess knowledge, attitudes, and practices related to SCD in a tribal region of Jashpur, Chhattisgarh, India. Methods: A community-based cross-sectional study was conducted in Gamhariya village, Jashpur district, from February to May 2025. A total of 338 adults (≥18 years), screened at least once for SCD, were selected using systematic sampling. Data were collected via structured interviews and analysed using SPSS v26. Chi-square tests identified associations between socio-demographic factors and knowledge levels. Results: Among participants (mean age: 43.7 ± 15.02 years), 96.7% had heard of SCD; however, only 39.1% correctly identified its genetic cause. Misconceptions about transmission were widespread, with 46.2% attributing the spread to blood transfusions. Attitudes revealed no support for pre-marital testing (100%). All participants were willing to undergo screening if services were available locally. Education and occupation were significantly associated with knowledge levels ($p < 0.05$). Conclusion: Despite high awareness of SCD, misconceptions prevail in this tribal population. Addressing these gaps through health education interventions is crucial for empowering communities for early detection.***

Keywords: Sickle cell disease, SCD, Sickle cell trait, tribal health, knowledge-attitude-practice, Chhattisgarh

1. Introduction

Sickle cell disease (SCD) is a hereditary hemoglobinopathy caused by a mutation in the β-globin gene, leading to the production of sickle haemoglobin (HbS).[1] It follows an autosomal recessive pattern, where individuals inheriting the gene from both parents (SS) manifest the disease, while heterozygous carriers (AS) are referred to as having sickle cell trait.[2] According to the World Health Organisation, approximately 5% of the global population carries a gene responsible for haemoglobin disorders, and nearly 300,000 children are born each year with SCD.[3] SCD prevalence in India ranges from 5% to 34%, predominantly among tribal populations.[4] It is the second most common hemoglobinopathy in the country, following thalassemia.[5] In India, the sickle cell trait is prevalent in states such as Madhya Pradesh, Odisha, Andhra Pradesh, and Chhattisgarh, with a prevalence ranging up to 40%.[6] In Chhattisgarh alone, nearly 10 to 30% of individuals suffer from the disease, with a substantial proportion residing in tribal communities.[7]

The manifestations of SCD include chronic anaemia, recurrent pain episodes, increased susceptibility to infections, stroke, jaundice, delayed growth, and cognitive impairment. The disease often leads to severe complications that impact physical, educational, social, and economic development, as well as maternal and fetal outcomes.[8] SCD patients also have decreased life expectancy and a low quality of life.

SCD continues to be a major, yet under-discussed, health challenge in Chhattisgarh. Unlike other regions where genetic predisposition alone is emphasised, in Chhattisgarh, the burden of SCD is linked with socio-cultural dynamics, particularly among tribal communities. Despite improvements in treatment and community outreach, substantial gaps in awareness and the persistence of misconceptions hinder timely health-seeking behaviours. Assessing the knowledge, attitudes, and practices (KAP) of affected individuals is critical for designing appropriate and culturally sensitive public health interventions. In this context, the current study was undertaken in Jashpur district of Chhattisgarh, a region with a significant tribal population, to evaluate the KAP related to SCD. Understanding these dimensions will facilitate evidence-based strategies to enhance awareness in the communities.

2. Methodology

Study Setting, Design, and Duration: This cross-sectional study was conducted in Gamhariya village in Jashpur, Chhattisgarh, India, for four months from February to May 2025. This village is under the catchment area of the Gamhariya Ayushman Arogya Mandir, under the Primary Health Centre, Gholeng of Jashpur district (in the selected PHCs,> 50 % of the population were tribal). This village is about 450 km from Raipur, the capital city of Chhattisgarh.

Sample size: A total of 338 samples was estimated from the following formula:

$$n = \frac{z^2.p.(1-p)}{e^2}$$

Where:
Z = 1.96 ≈ 2 (For 95% Confidence Interval)

P (Prevalence of SCD in tribal communities of Chhattisgarh) = 30% [7]
e (Margin of Error) = 5%

Sampling: One house in the village was selected randomly, and every consecutive house was visited for any adults 18 years or older who had ever screened for SCD, till the sample size of 338 was achieved. One adult member from each household was interviewed.

Inclusion and Exclusion Criteria: Any individual who is a resident of the study village for the last five years and is above 18 years, and has been screened for SCD once in their lifetime, given consent to participate in the study, was included in the study.

Data Collection: Data was collected by the face-to-face interview method using a structured questionnaire in the local language (in Chhattisgarhi). Information regarding socio-demographic characteristics like age, gender, marital status, and knowledge, attitude and practices regarding SCD was recorded in a pre-designed and pre-tested proforma.

Ethical Clearance: Approval from the Institutional Ethics Committee was obtained. Permission to collect data was further obtained from the District Health Officer, Jashpur, Chhattisgarh, India. Informed consent was taken from each study subject after explaining the purpose of the study.

Statistical analysis: Data was analysed using statistical software SPSS version 26. Descriptive statistics (frequency and percentage) were used to summarise demographic characteristics of the study subjects. The Chi Square test was used wherever required, and a p-value < 0.05 was considered to
be statistically significant.

3. Result

A total of 338 individuals were recruited to assess the knowledge, attitude, and practice of SCD in the study. The mean age of the participants was 43.7 years, having 25.7% of participants in the 35 to 44 years. Gender distribution was almost equal, with 171 males (50.6%) and 167 females (49.4%). Most participants belonged to Scheduled Tribes (58.6%), followed by Other Backwards Classes (18.9%), Scheduled Castes (16.3%), and those from the General category (6.2%). Most of the participants were farmers (30.5%), followed by unemployed (22.8%) and labourers (21.0%). [Table 1]

Table 1: Demographic distribution of the participants

Demographic Variable	Frequency (n=338)	Percentage (%)
Age Category (Mean ± SD = 43.7 ± 15.02)		
18 to 24	34	10.1
25 to 34	72	21.3
35 to 44	87	25.7
45 to 54	60	17.8
>54	85	25.1
Gender		
Female	167	49.4
Male	171	50.6
Caste		
General	21	6.2
Other Backwards Classes	64	18.9
Scheduled Caste	55	16.3
Scheduled Tribe	198	58.6
Education		
Un Educated	164	48.5
Primary	37	10.9
Middle	69	20.4
Senior Secondary	40	11.8
Under Graduate	27	8.0
Post Graduate	1	0.3
Occupation		
Business	46	13.6
Farming	103	30.5
Govt Employee	12	3.6
Labour	71	21.0
Housewives	10	3.0
Private Sector Working	19	5.6
Unemployed	77	22.8
Marital Status		
No	21	6.2
Yes	317	93.8

The prevalence of sickle cell trait in the study population was found to be 2.4% (8 out of 338).

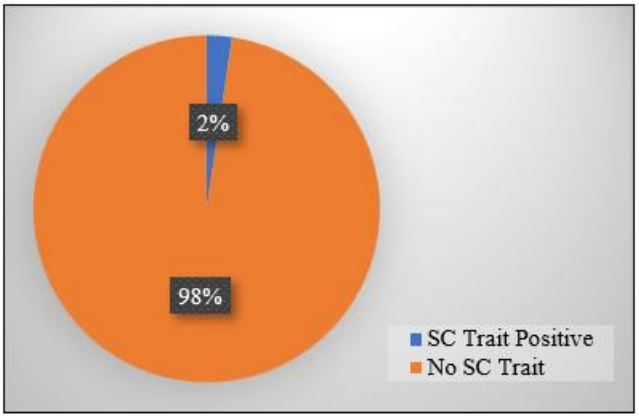

Figure 1: Prevalence of Sickle Cell Trait

Knowledge: The knowledge assessment showed that nearly all participants (96.7%) had heard of SCD. However, the understanding of its causes and transmission was not very clear among the participants. While 39.1% correctly identified it as a genetic condition, 37.9% incorrectly attributed it to infection, and 20.4% were unsure. Similarly, only 31.1% recognised inheritance as the mode of transmission, while 46.2% believed it spreads through blood transfusion. About 51.5% were aware that SCD can be diagnosed through testing. 53.3% believed that the disease could be managed with treatment. Awareness of government programs was high, with 83.4% being aware of them. Despite strong awareness, only 50.6% perceived SCD as a serious health problem. [Table 2]

Table 2: Distribution of Knowledge among the participants (n=338)

Variable	Frequency (n=338)	Percentage (%)
Have you heard about SCD?		
No	11	3.3
Yes	327	96.7
What do you think causes SCD?		
Do not know	69	20.4
Genetic/inherited from parents	132	39.1
Infection	128	37.9
Poor hygiene	9	2.7
How is SCD transmitted?		
Airborne	6	1.8
Do not know	71	21.0
From parents to children	105	31.1
Through blood transfusion	156	46.2
Do you know if Sickle Cell can be diagnosed by a test?		
Do not know	68	20.1
No	96	28.4
Yes	174	51.5
Have you heard of the Sickle Cell screening test?		
No	11	3.3
Yes	327	96.7
Can SCD be managed with treatment?		
Do not know	104	30.8
No	54	16.0
Yes	180	53.3
Are you aware of any government program for Sickle Cell screening/treatment in Chhattisgarh?		
No	56	16.6
Yes	282	83.4
Do you believe SCD is a serious health problem?		
No	167	49.4
Yes	171	50.6

Attitude: In terms of attitude, 74.0% reported they would take a family member with SCD to the hospital, while 3.0% preferred to hide the illness. About 67.2% expressed unwillingness to allow their child to marry someone with SCD. Notably, 87.3% rejected the idea that SCD is a curse. All participants (100.0%) supported pre-marital SCD testing. However, 27.8% believed people with SCD should not be treated equally in society. [Table 3]

Table 3: Distribution of Attitude among the participants (n=338)

Variable	Frequency (n=338)	Percentage (%)
If someone in your family has SCD, would you:		
Hide the illness	10	3.0
Take them to the hospital	250	74.0
Use traditional medicine only	78	23.1
Would you allow your child to marry someone with Sickle Cell Trait or Disease?		
No	227	67.2
Not Sure	107	31.7
Yes	4	1.2
Do you believe SCD is a curse or punishment?		
No	295	87.3
Yes	43	12.7
Should couples get tested for Sickle Cell before marriage?		
No	338	100.0
Do you think people with SCD should be treated equally in society?		
No	94	27.8
Yes	244	72.2

Practice: All participants (100.0%) had either undergone screening for SCD or had a family member screened, and all expressed willingness to get tested if services were offered in their local area. Most screening took place at health camps (79.0%), followed by sub-health centres (13.9%) and district hospitals (6.2%). Among the diagnosed, all reported taking folic acid treatment. [Table 4].

Table 4: Distribution of Practice among the participants (n=338)

Variable	Frequency (n=338)	Percentage (%)
Are you willing to get tested for SCD if services are provided in your area?		
Yes	338	100.0
Have you or your family members been screened for SCD?		
Yes	338	100.0
Where was it done?		
District Hospital	21	6.2
Health Camp	267	79.0
Primary Health Centre	3	0.9
Sub Health Centre	47	13.9
If screened, what was the result?		
Carrier (Trait)	8	2.4
Normal	330	97.6
If diagnosed, are you taking or providing any treatment or care?		
Not Applicable	330	97.6
Yes (Folic Acid)	8	2.4

Education and occupation showed a significant association with SCD status. Other variables such as age, gender, caste, and marital status did not show statistically significant associations with SCD, indicating no strong demographic trends in the study village. [Table 5]

Table 5: Association of Sickle Cell Trait with Socio-demographic Factors

Variable	No (n=330)	Yes (n=8)	Total	P Value	Chi-Square
Age Category					
18 to 24	32	2	34	0.123	7.260
25 to 34	70	2	72		
35 to 44	83	4	87		
45 to 54	60	0	60		
>54	85	0	338		
Gender					
Female	161	6	167	0.143	2.147
Male	169	2	171		
Caste					
General	21	0	21	0.700	2.193
OBC	61	3	64		
SC	54	1	55		
ST	194	4	198		
Education					
Un Educated	163	1	164	**0.003**	18.276
Primary	33	4	37		
Middle	69	0	69		
Senior Secondary	39	1	40		
UG	25	2	27		
PG	1	0	1		
Occupation					
Business	46	0	46	**0.011**	16.646
Farming	102	1	103		
Govt Employee	10	2	12		
Labour	70	1	71		
Not Applicable	9	1	10		
Private Sector Working	19	0	19		
Unemployed	74	3	77		
Marital Status					
No	20	1	21	0.594	1.041
Yes	310	7	317		

4. Discussion

To eliminate SCD, the National Sickle Cell Anaemia Elimination Mission (NSCAEM) was launched by the Government of India in 2023.[9] This mission was aimed at reducing the prevalence of SCD through awareness creation, targeted screening in the age group of 0-40 years in the affected districts of the tribal areas. The prevalence of sickle cell trait in the present study was around 3%, which is much lower than the state's prevalence, i.e., 10%.[10] A study by Rao et al. found the prevalence of sickle cell trait to be 6.20% in the Indian population.[11] In Chhattisgarh, sickle cell trait prevalence was more than 10 per cent in Abhujmaria, Gond, Halba tribes and Ghasia, Mahar and Ganda caste communities.[12]

The present study aims to explore the knowledge, attitude, and practice toward SCD among individuals in the Jashpur district of Chhattisgarh. Most of the participants were aware of SCD, which may be due to the screening camps in the village area under the NSCAEM. However, the information about the disease was prevalent among the participants, but the participants were not much aware of the cause, treatment, and management of the disease. In a similar study by Patil et al. noted a lack of correct knowledge about SCD in the tribal high-risk population.[13] In contrast, a study by Namajja et al. found that 71% of their study participants were aware of the SCD management.[14]

In the present study, all the participants think that pre-marital screening for SCD is not necessary. This may be due to the lack of knowledge and the belief that SCD is a non-genetic disorder in almost 61% of the participants. Although 100% of participants believed it to be a disease and not a curse by God, yet the majority, i.e., 61%, either do not know or believe that SCD is caused by poor hygiene and is an infectious disease. In contrast, a similar study done by Al-Qattan et al. in Saudi Arabia showed that 91.5% agreed to the premarital screening in the future.[15] It may be concluded that the acceptance of the premarital screening of the disease is associated with the knowledge level of the participants.

Among the study participant, there was a positive response and acceptance towards the screening and testing services available for SCD in their local area. All the participants agreed to get tested and take the required treatment for the disease if the treatment facility is available in the local area, implying the commitment of the community towards the disease. This implies that for the people residing in a village, accessibility of the health facility is a major predictor for screening, testing, treatment, and follow-up.

5. Study Limitation

The study was done in a single village located in Jashpur. Hence, the finding cannot be generalised to the population. Also, the data is self-reported, and thereby, the study has reporting bias inherent in it.

6. Conclusion

The study shows that the participants have ever heard of SCD, mostly due to the screening program by the government in their village. But most of the community lacks knowledge about the cause of the disease and treatment modalities. The study also showed socio-demographic indicators like education and occupation as predictors for poor knowledge. The policymakers may think of the implementation of interventions aiming at increasing the knowledge about the cause, symptoms, treatment, care, and management of the disease in SCD-endemic tribal areas.

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