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Knowledge, Attitudes, and Practices Regarding Sickle Cell Anaemia in Rural Maharashtra: A Community-Based Cross-Sectional Study

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ABSTRACT

Background: Sickle Cell Anaemia (SCA) carries a disproportionate burden among tribal communities in Maharashtra, India. The National Sickle Cell Anaemia Elimination Mission (2023) depends critically on community knowledge and preparedness. This study assessed knowledge, attitudes, and practices (KAP) regarding SCA among adults in rural Thane district.

Methods: A community-based cross-sectional study was conducted among 416 adults aged ≥18 years residing in the rural field practice area (Rural Health Training Centre) of Thane district over nine months. Participants were selected by systematic random sampling. Data were collected using a pre-tested, interviewer-administered bilingual structured questionnaire covering 12 knowledge, 8 attitude, and 10 practice items. Socio-economic status was classified by the Modified Kuppuswamy Scale. Chi-square tests and multivariate binary logistic regression were used for analysis (JAMOVI v2.7.13.0; $p<0.05$).

Results: The mean age was 37.5±14.97 years; females comprised 51.4%. Poor knowledge (score 0–4/12) was noted in 65.4%, while only 22.4% had good knowledge. Awareness of the hereditary nature of SCA was limited to 31.2%. Despite this, 75.5% demonstrated positive attitudes and 50.0% had average practice scores. On multivariate logistic regression, medium education (aOR=5.65, 95% CI: 2.78–11.46, $p<0.001$) and high education (aOR=9.04, 95% CI: 3.91–20.93, $p<0.001$) were the strongest independent predictors of adequate knowledge, while male sex was inversely associated (aOR=0.53, 95% CI: 0.33–0.84, $p=0.007$).

Conclusions: A significant knowledge-attitude-practice gap exists among rural adults in Thane district. Education emerged as the strongest predictor of SCA knowledge. Targeted community-based health education, strengthened outreach by community health workers, and integration of SCA counselling into existing primary care platforms are urgently required.

Keywords: *Sickle cell anaemia; KAP study; community-based; Thane; Maharashtra; elimination mission.*

INTRODUCTION

Sickle Cell Anaemia (SCA) arises from a single nucleotide substitution in the beta-globin gene (HBB), producing abnormal haemoglobin S (HbS) that polymerises under low-oxygen conditions. The resultant rigid, sickle-shaped erythrocytes cause chronic haemolytic anaemia, recurrent vaso-occlusive crises, and progressive multiorgan damage [1,2].

Globally, around 7.74 million individuals live with SCA, representing a 41% rise in prevalence over two decades, rendering it among the most burdensome severe monogenic disorders worldwide [3]. The World Health Organization recognises SCA as a significant contributor to under-five mortality, particularly in low- and middle-income countries [4].

India shoulders the second-largest global burden of SCA, with disease disproportionately concentrated among Scheduled Tribe (ST) and Scheduled Caste (SC) populations—earning it the label of a "tribal disease." The disease-endemic corridor, commonly termed the "Sickle Cell Belt," spans Maharashtra, Madhya Pradesh, Chhattisgarh, and Odisha [5,6]. Approximately 1 in 86 births among tribal communities is affected. The historical overlap of the sickle cell gene with malaria endemicity

sustained gene frequency through heterozygote advantage; however, as malaria incidence declines, SCA has emerged as a dominant public health concern [7].

Maharashtra ranks third nationally for SCA burden. Thane district, characterised by concurrent rapid urbanisation and significant tribal pockets—including the Warli and Katkari communities—presents a dual challenge of healthcare accessibility and disease awareness [8]. Notwithstanding intensified screening initiatives under the National Health Mission (NHM) Maharashtra, a substantial proportion of carriers and patients remain undiagnosed, owing partly to the asymptomatic nature of the sickle cell trait and inadequate community-level awareness [9].

Responding to this burden, the Government of India launched the National Sickle Cell Anaemia Elimination Mission in 2023, targeting elimination of SCA as a public health problem by 2047 through universal neonatal screening, genetic counselling, and comprehensive care [10]. The success of such an initiative is inherently contingent on community KAP. Prior research in Maharashtra and Gujarat has documented a prominent knowledge-practice gap, with misconceptions about transmission, stigmatisation of affected individuals, and continued recourse to traditional healing systems [11,12].
Despite documented biological prevalence data, recent community-based KAP studies specific to the rural adult population of Thane district remain scarce. This study aimed to assess KAP regarding SCA in this population and identify socio-demographic predictors of adequate knowledge, thereby informing district-level implementation of the elimination mission.

METHODS

Study design and setting

A community-based cross-sectional study was conducted in the rural field practice area attached to the Department of Community Medicine, Rajiv Gandhi Medical College and Chhatrapati Shivaji Maharaj Hospital. Specifically, the study area comprised 14 villages under three sub-centres (Anjur, Vehale, and Dapode) of the Primary Health Centre (PHC) Diva Anjur, Taluka Bhiwandi, District Thane. According to the updated village-wise registry, the total population of this area is 39,966, encompassing 8,614 households. The study followed the STROBE (Strengthening the Reporting of Observational Studies in Epidemiology) guidelines for reporting.

Duration

The study was conducted over a period of nine months, from August 2025 to April 2026.

Study population and eligibility criteria

The study population comprised adults of both sexes aged 18 years or above who were permanent residents of the selected rural area and provided written informed consent. Individuals who were critically ill or cognitively unable to understand the questionnaire, those who declined consent, and medical or paramedical professionals residing in the area were excluded. Additionally, individuals previously screened for Sickle Cell Anaemia were excluded from the study population to prevent baseline knowledge bias.

Sample size

Sample size was estimated using Cochran's formula for a single proportion, based on a reference prevalence of 57.1% basic SCA knowledge reported by Deshmukh et al.[13] from Amravati district, Maharashtra ($p=0.57$, $q=0.43$, $d=0.05$, $Z=1.96$, 95% confidence level). The minimum required sample was 377; adding a 10% non-response buffer yielded a final sample size of 416 participants.

Sampling technique

A systematic random sampling technique was employed to select households. The sampling frame consisted of the updated household list from PHC Diva Anjur, totalling 8,614 households. With a calculated sample size of 416, the sampling interval (k) was determined as N/n ($8,614 \div 416 \approx 21$). Therefore, every 21st household was selected from the list. The first household was chosen randomly between 1 and 21 using a random number table. One eligible adult per selected household was interviewed; if more than one eligible individual was present, the participant was selected using a simple lottery method to minimise selection bias.

Data collection tool and process

A structured, interviewer-administered questionnaire—prepared in English and translated into Marathi and Hindi for local comprehension—was used for data collection. The questionnaire comprised four sections: (i) socio-demographic information including socio-economic status (SES) classified by the Modified Kuppuswamy Scale; (ii) 12-item knowledge section (multiple choice and Yes/No format; maximum score 12); (iii) 8-item attitude section using a five-point Likert scale (maximum score 32, scored 0–4 per item); and (iv) 10-item practice section (maximum score 10). The questionnaire was pre-tested on 40 adults outside the study area, and necessary revisions were incorporated. Internal consistency of the attitude section was assessed using Cronbach's alpha coefficient ($\alpha=0.837$), indicating good reliability; the knowledge ($\alpha=0.961$) and practice ($\alpha=0.706$) sections also demonstrated acceptable to excellent internal consistency. Data were collected through face-to-face interviews by trained field researchers.

Score classification
Knowledge scores were classified as: poor (0–4), average (5–8), and good (9–12). Attitude scores were classified as: negative (0–15), neutral (16–24), and positive (25–32). Practice scores were classified as: poor (0–3), average (4–6), and good (7–10).

Statistical analysis
Data were entered and analysed using JAMOVI version 2.7.13. Descriptive statistics—frequencies, percentages, means, and standard deviations—were computed for all variables. The chi-square goodness-of-fit test assessed distributional significance within categorical variables; the chi-square test of independence examined bivariate associations between socio-demographic characteristics and KAP categories. Multivariate binary logistic regression was performed to identify independent predictors of adequate knowledge (dichotomised as poor versus good/average), with results expressed as adjusted odds ratios (aOR) with 95% confidence intervals (CI). Predictor variables were selected on theoretical grounds and bivariate significance. A p-value <0.05 was considered statistically significant.

RESULTS
Socio-demographic profile
A total of 416 adults participated in the study. The mean age was 37.5±14.97 years. The 26–35-year age group was most represented (29.6%), followed by the ≥46-year group (26.9%); the age distribution showed statistically significant variation (p=0.014). Females comprised 51.4%; the sex distribution was not statistically significant (p=0.556). Married individuals constituted 81.2% (p<0.001). The majority of household heads had completed high school (23.1%) or an intermediate/diploma course (19.7%), while 8.7% were illiterate (p<0.001). Occupation-wise, elementary occupations (26.9%) and unemployment (26.0%) were most common (p<0.001). Upper middle (39.7%) and lower middle class (36.5%) were the predominant socio-economic strata (p<0.001). Detailed characteristics are presented in Table 1.

Table 1: Socio-demographic characteristics of study participants (N=416)

S.No	Characteristic	Frequency (n)	Percentage (%)	p-value
1	**Age (years)**			0.014
	18–25 years	103	24.8	
	26–35 years	123	29.6	
	36–45 years	78	18.8	
	≥46 years	112	26.9	
2	**Sex**			0.556
	Female	214	51.4	
	Male	202	48.6	
3	**Marital Status**			<0.001
	Married	338	81.2	
	Unmarried	38	9.1	
	Widowed	21	5.0	
	Single	15	3.6	
	Divorced	4	1.0	
4	**Education (Head of Household)**			<0.001
	Illiterate	36	8.7	
	Primary school	24	5.8	
	Middle school	70	16.8	
	High school	96	23.1	

	Intermediate/Diploma	82	19.7	
	Graduate	74	17.8	
	Postgraduate/Professional	34	8.2	
5	**Occupation (Head of Household)**			<0.001
	Elementary occupation	112	26.9	
	Unemployed	108	26.0	
	Professional	56	13.5	
	Craft & related trade workers	38	9.1	
	Skilled/shop-market sales	28	6.7	
	Technicians & associate professionals	28	6.7	
	Skilled agricultural/fishery workers	14	3.4	
	Clerical workers	14	3.4	
	Plant/machine operators	8	1.9	
	Legislators/senior officials	8	1.9	
6	**Socio-Economic Status (Modified Kuppuswamy Scale)**			<0.001
	Upper class	17	4.1	
	Upper middle class	165	39.7	
	Lower middle class	152	36.5	
	Upper lower class	80	19.2	

Chi-square goodness-of-fit test used. $p<0.05$ considered statistically significant.

Knowledge about Sickle Cell Anaemia

Overall SCA awareness was low. Only 35.1% of participants had ever heard of SCA (K1), and merely 31.2% recognised it as a hereditary disease (K6). Knowledge of carrier status (K4) and the carrier-patient distinction (K12) were the least understood items (17.3% each). Awareness of government-disseminated SCA information (K9) was strikingly poor at 17.8%. The only item that did not show statistically significant deviation from equal distribution was K11—whether a person with SCA can lead a normal life with treatment (52.4%, p=0.327). All other items showed significantly higher proportions of No/Don't Know responses (p<0.001). Item-wise responses are detailed in Table 2.

Table 2: Item-wise distribution of knowledge about SCA among study participants (N=416)

Q.	Question	Yes n (%)	No/Don't Know n (%)	Prevalence (%)	p-value
K1	Have you ever heard about Sickle Cell Anaemia?	146 (35.1)	270 (64.9)	35.1	<0.001
K2	Do you know how Sickle Cell Anaemia occurs?	124 (29.8)	292 (70.2)	29.8	<0.001
K3	Can SCA be transmitted by marrying an affected person?	130 (31.2)	286 (68.8)	31.2	<0.001
K4	Do you know who is called a carrier of Sickle Cell?	72 (17.3)	344 (82.7)	17.3	<0.001
K5	If both partners are carriers, can their child have SCA?	106 (25.5)	310 (74.5)	25.5	<0.001

K6	Is Sickle Cell Anaemia a hereditary disease?	130 (31.2)	286 (68.8)	31.2	<0.001
K7	Is Sickle Cell Anaemia present from birth?	140 (33.7)	276 (66.3)	33.7	<0.001
K8	Are joint pain and fatigue symptoms of SCA?	134 (32.2)	282 (67.8)	32.2	<0.001
K9	Have you received information about SCA from government officials?	74 (17.8)	342 (82.2)	17.8	<0.001
K10	Can bone marrow transplant in childhood cure SCA?	120 (28.8)	296 (71.2)	28.8	<0.001
K11	Can a person with SCA live a normal life with proper treatment?	218 (52.4)	198 (47.6)	52.4	0.327
K12	Do you know the difference between a SCA carrier and a patient?	72 (17.3)	344 (82.7)	17.3	<0.001

SCA: Sickle Cell Anaemia. Chi-square goodness-of-fit test (Yes vs. No/Don't Know). p<0.05 considered statistically significant.

Knowledge score classification

When scored cumulatively, 65.4% of participants fell in the poor knowledge category (score 0–4 out of 12), while only 22.4% had good knowledge (score 9–12) and 12.3% had average knowledge (score 5–8). This distribution was highly statistically significant (p<0.001), indicating a severe deficit in SCA-related knowledge in the study population (Table 3).

Table 3: Classification of participants by knowledge score (N=416)

Category (Score)	Frequency	Percentage (%)	Prevalence (%)	p-value
Poor knowledge (0–4)	272	65.4	65.4	<0.001
Average knowledge (5–8)	51	12.3	12.3	
Good knowledge (9–12)	93	22.4	22.4	
Total	416	100.0	—	

Chi-square goodness-of-fit test across categories; p<0.001.

Attitude toward Sickle Cell Anaemia

In contrast to knowledge deficits, attitudes toward SCA were largely positive. Three-quarters of participants (75.5%) demonstrated a positive attitude (score 25–32 out of 32), while 24.5% had a neutral attitude (score 16–24). Notably, no participant (0.0%) exhibited a negative attitude score. This distribution was statistically significant (p<0.001) and suggests that stigma and discrimination toward SCA patients are not prevalent at the attitudinal level in this population (Table 4).

Table 4: Classification of participants by attitude score (N=416)

Category (Score)	Frequency	Percentage (%)	Prevalence (%)	p-value
Negative attitude (0–15)	0	0.0	0.0	<0.001
Neutral attitude (16–24)	102	24.5	24.5	
Positive attitude (25–32)	314	75.5	75.5	
Total	416	100.0	—	

Chi-square goodness-of-fit test across categories; p<0.001.

Practices related to Sickle Cell Anaemia

Practice scores occupied an intermediate position. Half the participants (50.0%) had average practice scores (4–6 out of 10), 38.9% had poor practice scores (0–3), and only 11.1% demonstrated good practices (7–10). This distribution was

statistically significant (p<0.001), underscoring that positive attitudes do not automatically translate into appropriate preventive behaviours in the absence of adequate knowledge and enabling health system factors (Table 5).

Table 5: Classification of participants by practice score (N=416)

Category (Score)	Frequency	Percentage (%)	Prevalence (%)	p-value
Poor practice (0–3)	162	38.9	38.9	<0.001
Average practice (4–6)	208	50.0	50.0	
Good practice (7–10)	46	11.1	11.1	
Total	416	100.0	—	

Chi-square goodness-of-fit test across categories; p<0.001.

Multivariate logistic regression: Predictors of adequate knowledge

Table 6 presents results from the multivariate binary logistic regression with good/average knowledge as the outcome. On adjusted analysis, educational attainment was the strongest independent predictor. Compared with participants with low education (illiterate to middle school), those with medium education (high school/intermediate) had more than five-fold higher odds of adequate knowledge (aOR=5.65, 95% CI: 2.78–11.46, p<0.001), and those with high education (graduate/postgraduate) had more than nine-fold higher odds (aOR=9.04, 95% CI: 3.91–20.93, p<0.001). Male sex was inversely associated with adequate knowledge compared with female sex (aOR=0.53, 95% CI: 0.33–0.84, p=0.007). Socio-economic status and age group did not reach independent statistical significance after controlling for education and sex.

Table 6: Multivariate binary logistic regression for predictors of adequate SCA knowledge (Good/Average vs. Poor) (N=416)

Variable	aOR	95% CI	p-value
Education (Reference: Low)			
Medium (High school/Intermediate)	5.65	2.78–11.46	<0.001
High (Graduate/Postgraduate)	9.04	3.91–20.93	<0.001
Sex (Reference: Female)			
Male	0.53	0.33–0.84	0.007
Age group (Reference: 18–25 years)			
26–35 years	1.35	0.73–2.47	0.335
36–45 years	0.75	0.37–1.53	0.435
≥46 years	0.54	0.28–1.03	0.061
Socio-economic status (Reference: Upper lower class)			
Lower middle class	1.62	0.74–3.53	0.230
Upper middle class	1.95	0.87–4.36	0.106
Upper class	2.42	0.65–9.00	0.186

aOR: adjusted odds ratio; CI: confidence interval. Binary logistic regression with adequate knowledge (good/average score) as outcome. Reference categories shown in parentheses.

DISCUSSION

This community-based KAP study among 416 rural adults in Thane district reveals a stark deficiency in SCA-related knowledge, paradoxically positive attitudes, and intermediate preventive practices—a pattern consistent with the classical KAP gap documented extensively in health behaviour research [14].

Knowledge

The finding that only 35.1% of participants had ever heard of SCA is concerning for a district with a documented SCA burden. This awareness level is markedly lower than the 57.1% reported by Deshmukh et al.[13] in Amravati and the 72.3% noted by Tayade and Tayade[15] in a student cohort. The broader community-based sampling in the present study—which included illiterate and low-socio-economic strata respondents—likely accounts for the lower awareness. Only 31.2% of participants recognised SCA as hereditary—a concept central to pre-marital and pre-conceptional counselling—and a mere 17.3% could distinguish a carrier from a patient, the lowest knowledge scores recorded. This is of direct relevance to elimination mission goals, as carrier awareness is a prerequisite for effective pre-marital screening.

Low awareness of government-disseminated SCA information (17.8%) suggests that existing Information, Education, and Communication campaigns have not adequately penetrated the rural population. This parallels findings by Patil and Thikare[12] and Boyd and Galadanci[16], who highlighted that social determinants and weak health system outreach contribute to knowledge gaps in comparable settings.

Attitude

In stark contrast to knowledge deficits, 75.5% of participants demonstrated positive attitudes and no respondent scored in the negative attitude range. This finding differs from earlier reports documenting discrimination against SCA patients in rural communities [12] and may reflect a relatively non-stigmatising social environment in the RHTC catchment area. The complete absence of negative attitudes is a significant facilitating factor for health behaviour change; however, positive attitudes without commensurate knowledge may result in superficial compliance with screening recommendations rather than informed preventive behaviour.

Practice

Practice scores were intermediate, with 50.0% in the average category and 38.9% in the poor category. The pronounced gap between high positive attitudes (75.5%) and low good practices (11.1%) exemplifies the KAP paradox, wherein willingness does not automatically translate into appropriate behaviour without enabling conditions—including accessible screening facilities, community health worker support, and sustained education [14]. These findings align with those of Gamit and Kantharia[11], who documented comparable attitude-practice disconnects in Gujarat.

Multivariate predictors of knowledge

Multivariate logistic regression identified educational attainment as the strongest independent predictor of adequate SCA knowledge: compared with low-education participants, those with medium and high education had 5.65-fold (95% CI: 2.78–11.46) and 9.04-fold (95% CI: 3.91–20.93) higher adjusted odds, respectively ($p<0.001$). This finding reinforces the well-established role of formal education in health literacy and is consistent with the broader literature on KAP studies in haemoglobinopathies [17,18]. The inverse association between male sex and adequate knowledge (aOR=0.53, 95% CI: 0.33–0.84, $p=0.007$) is noteworthy, and may reflect the higher healthcare-seeking behaviour and health information exposure among women in the rural RHTC area, possibly through antenatal care and ASHA worker interactions. Socio-economic status did not emerge as an independent predictor after adjusting for education, suggesting that the effect of SES on knowledge may be largely mediated through educational attainment.

Implications for the National Elimination Mission

The National Sickle Cell Anaemia Elimination Mission (2023) targets elimination by 2047 through universal neonatal screening, pre-marital counselling, and comprehensive care [10]. The findings of this study indicate that community readiness in rural Thane—though attitudes are favourable—is constrained by severely inadequate knowledge, particularly regarding hereditary transmission and carrier identification. Targeted IEC campaigns using locally relevant media, peer health educators, and integration of SCA counselling into existing antenatal and primary care platforms are urgently required [19,10].

Strengths and limitations

Strengths of this study include its community-based design, adequate sample size, pre-tested bilingual questionnaire, and the use of multivariate analysis to identify independent predictors. Limitations include the cross-sectional design precluding causal inference, restriction to a single RHTC area limiting generalisability to urban or tribal Thane populations, and potential social desirability bias in attitude and practice responses.

CONCLUSION

A significant knowledge-attitude-practice gap regarding Sickle Cell Anaemia exists among rural adults in Thane district, Maharashtra. Educational attainment emerged as the strongest independent predictor of adequate knowledge, while male sex was inversely associated. Critical knowledge domains—including hereditary transmission, carrier status, and the carrier-patient distinction—remain severely deficient, and government health outreach has been largely ineffective in reaching this population. Targeted community-based health education, strengthened screening infrastructure, integration of SCA counselling into primary care, and training of community health workers are essential to bridge this gap and support the objectives of the National Sickle Cell Anaemia Elimination Mission.

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