Dr. Shahla Khan., 2026, 14:4
ISSN (Online): 2348-4098
ISSN (Print): 2395-4752

International Journal of Science, Engineering and Technology
An Open Access Journal

Barriers to Early Diagnosis and Healthcare Access among Tribal Communities Affected by Sickle Cell Disease in Chhattisgarh: Implications for Community-Based Outreach Programs

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Abstract- Background: Sickle Cell Disease (SCD) remains highly prevalent among tribal populations in central India. This study evaluated barriers to early diagnosis and healthcare access in selected tribal districts of Chhattisgarh using structured interviews. Methods: A community-based cross-sectional observational study included 500 participants with confirmed SCD or caregivers of affected individuals from Mahasamund, Kanker, Jashpur, and Bastar districts. Information on awareness, healthcare utilization, diagnostic delay, and barriers to care was collected using a structured interviewer-administered questionnaire and analysed using descriptive statistics. Results: The principal barriers to healthcare access were long distance to health facilities (41.6%), financial constraints (35.2%), transportation problems (31.8%), lack of specialist services (29.6%), lack of awareness (27.4%), and language/cultural barriers (19.2%). Diagnostic delay was 1–3 years in 36.8% of participants, 3–5 years in 28.4%, and more than 5 years in 15.6%; the reported mean diagnostic delay was 3.2 ± 1.8 years. Only 38.2% reported regular follow-up visits, while 45.6% reported missed appointments due to financial reasons. Conclusion: Community-based outreach, decentralized diagnostic services, strengthened referral systems, frontline health-worker engagement, and improved financial and transportation support are important to improve equitable SCD care in tribal regions of Chhattisgarh.

Keywords— Sickle Cell Disease; Tribal Health; Healthcare Access; Community Outreach; Chhattisgarh; Public Health

I. INTRODUCTION

Sickle Cell Disease is one of the most common severe inherited haemoglobin disorders worldwide. India bears a substantial burden, with a particularly important impact among tribal communities. Evidence from India has documented substantial geographic and socioeconomic variation in disease burden and continuing gaps in access to diagnosis and care. [1–4]

In geographically dispersed and predominantly rural populations, access to specialist services may be constrained by travel distance, transportation difficulties, financial limitations, and gaps in disease awareness. Health-systems reviews and community-based studies in India have emphasized the importance of decentralized screening, frontline health-worker engagement, referral pathways, and context-specific community interventions. [4–8]

The present study investigated barriers affecting early diagnosis and healthcare access among individuals with SCD and their caregivers in selected tribal districts of Chhattisgarh, with the aim of informing evidence-based community outreach and referral interventions.

Objectives

Primary objective: To identify barriers affecting early diagnosis and healthcare access among tribal populations affected by SCD in Chhattisgarh.

Secondary objectives: To assess awareness, health-seeking behaviour, socioeconomic barriers, and the contribution of community outreach programmes.

II. MATERIALS AND METHODS

Study Design and Setting

This was a community-based cross-sectional observational study conducted in Mahasamund, Kanker, Jashpur, and Bastar districts of Chhattisgarh.

Study Population

The study population comprised individuals with confirmed SCD and caregivers of affected individuals residing in the selected study districts.

Eligibility Criteria

Inclusion criteria were confirmed SCD, residence in a study district, and willingness to participate in the interview. Exclusion criteria were refusal to participate, incomplete interview responses, duplicate records, or unreliable interview data.

Data Collection

Data were collected using a structured interviewer-administered questionnaire covering awareness of SCD, health-seeking behaviour, healthcare utilization, diagnostic delay, and barriers to accessing care. The final dataset included 500 participants.

Ethical Considerations

The analysis used anonymized interview data collected during community outreach activities. No biological specimens were collected and no intervention was performed as part of this analysis. Participant confidentiality was maintained. The source manuscript does not provide an ethics committee approval number; this should be supplied if institutional ethics approval was obtained and is required by the target journal.

Data Analysis

Data were coded and analysed using descriptive statistics. Frequencies and percentages were calculated for categorical variables. Diagnostic delay was summarized using the reported mean and standard deviation.

Methodology Flow

Study area selection → Community outreach → Identification of eligible participants → Structured interview → Data verification → Coding and statistical analysis → Interpretation → Recommendations

III. RESULTS

Participant Characteristics

A total of 500 participants with confirmed SCD or caregivers of affected individuals were enrolled from Mahasamund, Kanker, Jashpur, and Bastar districts. Of the participants, 53.0% were male and 47.0% were female. Participants aged 18–30 years constituted 42.4% of the sample, while 33.6% were aged 31–45 years and 24.0% were aged above 45 years. Tribal-community participants represented 79.6% of the sample, and 88.4% reported rural residence. More than half (57.2%) had primary education or less.

Table 1. Sociodemographic characteristics of participants (N = 500)

Variable	Frequency	Percentage (%)
Male	265	53.0
Female	235	47.0
Age 18–30 years	212	42.4
Age 31–45 years	168	33.6
Age >45 years	120	24.0
Tribal Communities	398	79.6
Rural Residence	442	88.4
Primary Education or Less	286	57.2
Secondary Education	156	31.2
Graduate and Above	58	11.6

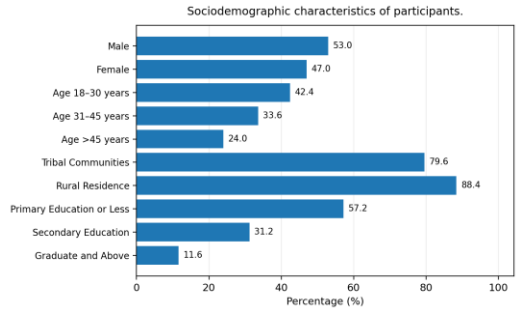

Figure 1. Sociodemographic characteristics of participants.

Interpretation: The sample was predominantly rural (88.4%) and comprised mainly participants from tribal communities (79.6%). Participants aged 18–30 years formed the largest age group (42.4%), while 57.2% had primary education or less.

Awareness Regarding Sickle Cell Disease

Awareness of SCD before diagnosis was reported by only 39.6% of participants. Knowledge that SCD is inherited was reported by 35.2%, while only 28.4% were aware of carrier screening. Awareness of complications was reported by 45.6%, and 33.4% were aware of government screening programmes.

Table 2. Awareness regarding Sickle Cell Disease

Indicator	Yes, n (%)	No, n (%)
Heard about SCD before diagnosis	198 (39.6)	302 (60.4)
Aware that SCD is inherited	176 (35.2)	324 (64.8)
Aware of carrier screening	142 (28.4)	358 (71.6)
Aware of complications	228 (45.6)	272 (54.4)
Aware of government screening programs	167 (33.4)	333 (66.6)

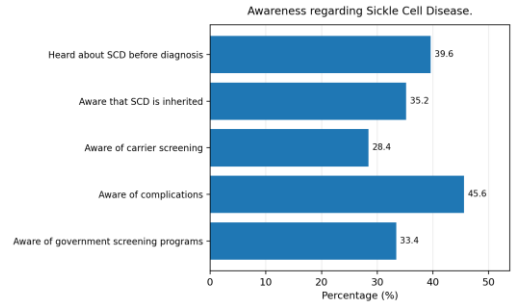

Figure 2. Awareness regarding Sickle Cell Disease.

Interpretation: Awareness was limited: fewer than half had heard about SCD before diagnosis (39.6%), and awareness of carrier screening (28.4%) and government screening programmes (33.4%) was particularly low.

Sources of information about SCD

ASHA workers were the most frequently reported source of information (33.6%), followed by government hospitals (24.2%), family members (19.2%), community camps (14.4%), and social media/internet sources (8.6%).

Table 3. Sources of information about SCD

Source	Frequency	Percentage (%)
ASHA Workers	168	33.6
Government Hospitals	121	24.2
Family Members	96	19.2
Community Camps	72	14.4
Social Media/Internet	43	8.6

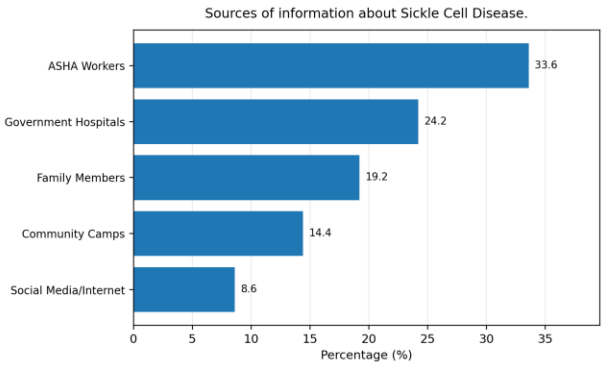

Figure 3. Sources of information about Sickle Cell Disease.

Interpretation: ASHA workers were the most frequently reported source of information (33.6%), followed by government hospitals (24.2%). Social media/internet contributed the smallest reported share (8.6%).

Barriers to Healthcare Access

The most commonly reported barrier was long distance to a health facility (41.6%), followed by

financial constraints (35.2%) and transportation problems (31.8%). Lack of specialist services, lack of awareness, and language/cultural barriers were also reported. Multiple responses were permitted.

Table 4. Barriers to healthcare access

Barrier	Frequency	Percentage (%)
Long Distance to Health Facility	208	41.6
Financial Constraints	176	35.2
Transportation Problems	159	31.8
Lack of Specialist Services	148	29.6
Lack of Awareness	137	27.4
Language/Cultural Barriers	96	19.2

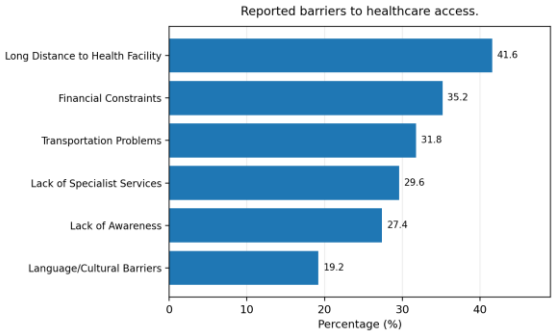

Figure 4. Reported barriers to healthcare access.

Interpretation: Geographic access was the leading reported barrier (41.6%), followed by financial constraints (35.2%) and transportation problems (31.8%). Multiple responses were permitted, so percentages are not expected to total 100%.

Delay in Diagnosis

The reported diagnostic delay was less than one year for 19.2% of participants, 1–3 years for 36.8%, 3–5 years for 28.4%, and more than 5 years for 15.6%. The mean diagnostic delay reported in the dataset was 3.2 ± 1.8 years.

Table 5. Delay in diagnosis

Time from symptoms to diagnosis	Frequency	Percentage (%)
<1 Year	96	19.2
1–3 Years	184	36.8
3–5 Years	142	28.4
>5 Years	78	15.6

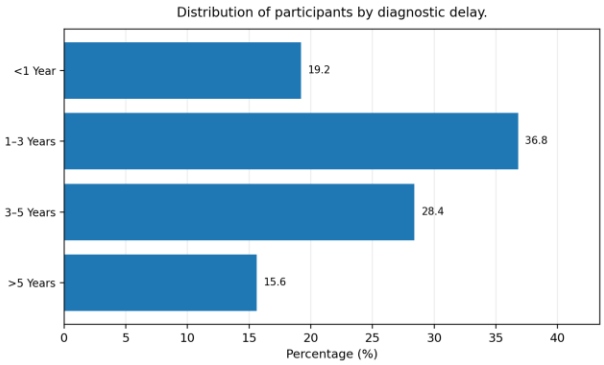

Figure 5. Distribution of participants by diagnostic delay.

Interpretation: The most common diagnostic-delay category was 1–3 years (36.8%). The 3–5-year and >5-year groups together accounted for 44.0% of participants, indicating that a substantial proportion experienced delays exceeding three years.

Healthcare Utilization

At least one hospitalization during the previous year was reported by 54.8% of participants. Regular follow-up visits were reported by 38.2%, while 59.2% reported Hydroxyurea treatment and 33.4% reported a history of blood transfusion. Financial constraints contributed to missed appointments for 45.6% of participants.

Table 6. Healthcare utilization

Variable	Frequency	Percentage (%)
At least one hospitalization in previous year	274	54.8
Regular follow-up visits	191	38.2
Hydroxyurea treatment	296	59.2
Blood transfusion history	167	33.4
Missed appointments due to financial reasons	228	45.6

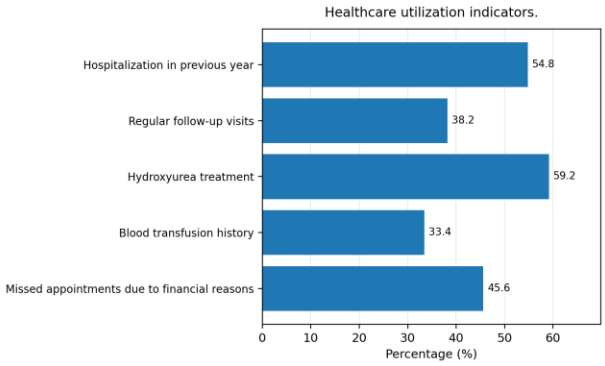

Figure 6. Healthcare utilization indicators.

Interpretation: Hydroxyurea treatment was reported by 59.2% of participants and hospitalization during the previous year by 54.8%. Regular follow-up was reported by only 38.2%, while 45.6% reported missing appointments for financial reasons.

IV. DISCUSSION

The findings demonstrate persistent inequities in access to SCD care among populations from selected tribal districts of Chhattisgarh. Geographic isolation was the most frequently reported barrier, followed by financial hardship and transportation difficulties. These findings indicate that physical access to healthcare facilities remains an important determinant of timely diagnosis and continuity of care.

Limited awareness was also evident. Fewer than four in ten participants had heard about SCD before diagnosis, and fewer than one-third were aware of carrier screening or government screening programmes. These findings highlight the importance of sustained community education, genetic counselling, and family-based awareness activities. Evidence from tribal populations in India also supports the importance of early identification and screening for SCD. [13–15]

Frontline health workers, particularly ASHA workers, were the most frequently reported source of information. This finding supports strengthening the role of frontline workers in community-level education, referral, follow-up, and linkage with screening services.

Diagnostic delay was substantial, with 44.0% of participants reporting a delay of more than three years when the 3–5-year and >5-year categories are considered together. The reported mean diagnostic delay of 3.2 ± 1.8 years further emphasizes the need for earlier recognition and decentralized diagnostic pathways.

Only 38.2% reported regular follow-up, while 45.6% reported missing appointments because of financial reasons. These findings suggest that improving diagnosis alone may not be sufficient; continuity of care also requires accessible follow-up services, transportation support, affordable treatment, and reliable referral pathways. Recent evidence on healthcare-seeking behaviour among tribal populations and broader social determinants of SCD care similarly highlights the role of socioeconomic and access-related factors. [19,20] The use of Hydroxyurea in India has also been documented in systematic and clinical studies, underscoring the importance of maintaining access to evidence-based long-term treatment. [16–18]

Community outreach, ASHA-worker engagement, decentralized diagnostics, telemedicine, and implementation of national SCD programmes may help reduce diagnostic delays and improve continuity of care. Previous Indian implementation studies have demonstrated the feasibility of population-based screening through primary/community health systems and the value of community mobilization and health-worker capacity building. [6,7,9–12] Future multicentre studies incorporating inferential analyses would help identify factors independently associated with delayed diagnosis and inadequate healthcare utilization. These priorities are consistent with broader international strategies for improving outcomes in SCD. [21]

Strengths

Community-based data collection from selected high-prevalence tribal districts provides practical evidence relevant to improving outreach, screening, referral, and healthcare access services.

Limitations

The cross-sectional design, reliance on self-reported responses, inclusion of selected districts only, and use of descriptive analysis limit causal inference and generalizability. The study therefore describes reported barriers and healthcare experiences rather than establishing causal relationships.

V. CONCLUSION

Strengthening decentralized screening, genetic counselling, referral systems, frontline health-worker engagement, and community outreach is essential to improve early diagnosis and long-term care for populations affected by SCD in Chhattisgarh. Addressing geographic, financial, transportation, specialist-service, awareness, and language/cultural barriers should be central to community-based SCD programmes. The findings provide practical evidence for public health planning and may support future implementation of advanced therapies by improving identification, referral, and continuity of care.

Declarations

Ethics approval: No separate ethics committee approval was obtained for this analysis. The analysis used anonymized interview data collected during community outreach activities; no biological specimens were collected and no intervention was performed as part of this analysis. Participant confidentiality was maintained.

Consent to participate: The participants were willing to participate in the interview as an inclusion criterion, no separate consent was taken.

Conflicts of interest: No

Funding: This study was not funded by any external agency, institution, or commercial organization.

Acknowledgements

The authors gratefully acknowledge the support and cooperation of the Pt. Deendayal Upadhyaya Memorial Health Sciences and AYUSH University of Chhattisgarh, Raipur, and the participating community members and caregivers from Mahasamund, Kanker, Jashpur, and Bastar districts.

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