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AWARENESS AND PREVENTION KNOWLEDGE OF SICKLE CELL DISEASE AMONG FAMILIES OF AFFECTED CHILDREN IN CENTRAL INDIA: A HOSPITAL-BASED OBSERVATIONAL STUDY

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ABSTRACT

Background: Sickle cell disease (SCD) is a hereditary disorder with substantial burden in Central India. Families of affected children are pivotal for prevention behaviors such as carrier testing, premarital screening, and genetic counseling. This study assessed awareness related to prevention among family members of pediatric patients.

Materials and Methods: We conducted a hospital-based observational case-control study in the Department of Paediatrics at a tertiary care centre in Central India, over 12 months (10 October 2023–10 October 2024). Adult family members of children with SCD (≥2 years since diagnosis) were enrolled by convenience sampling. A pre-tested, structured questionnaire (20 MCQs; adapted from a published instrument) measured knowledge of inheritance, trait status, diagnostic testing, premarital/prenatal screening, and testing practices. Descriptive statistics were generated in IBM SPSS v22.

Results: We enrolled 240 respondents (56.7% male); most were 21–40 years (56.7%). Awareness that SCD is hereditary was 63.3%, and 43.3% recognized blood tests for diagnosis. Trait literacy was low: only 11.7% had heard of sickle cell trait. Knowledge of the correct carrier test (hemoglobin electrophoresis) was 18.3% (66.7% unsure; 15.0% selected CBC). Understanding of inheritance probabilities when both parents are carriers was limited (25.0% correct for trait; 10.0% correct for SCD). A common misconception was that SCD can occur if only one parent is a carrier (71.7% "Yes"). Prenatal screening awareness was 40.0%. In practice, self-testing was 21.7%, and testing among other relatives was 48.3%; nevertheless, 78.3% endorsed testing parents/siblings. Premarital screening was widely supported (83.3%). Overall, 75.0% believed SCD can be reduced/controlled through preventive measures.

Conclusions: Families showed foundational awareness and strong prevention-oriented attitudes, but critical gaps persist in trait literacy, knowledge of the correct diagnostic test, and understanding of Mendelian risk—gaps that likely contribute to low personal testing. Low-literacy education integrated into routine care, coupled with accessible carrier and prenatal screening, is needed to translate favorable attitudes into informed decisions and increased uptake of prevention services.

Keywords: Sickle cell disease; Family awareness; Carrier testing; Hemoglobin electrophoresis; Premarital screening; Prenatal screening; Genetic counseling; Inheritance risk; Central India; Tribal communities.

INTRODUCTION

Sickle cell disease (SCD) is a hereditary blood disorder that significantly impacts individuals and their families. It is caused by a mutation in the HBB gene, leading to the production of abnormal hemoglobin S (HbS), which results in red blood cells becoming rigid and sickle-shaped. These cells obstruct blood flow and cause chronic complications such as anemia, pain crises, and organ damage. SCD follows an autosomal recessive inheritance pattern, meaning that both parents must carry the sickle cell trait for their child to inherit the disease.[1] Given its genetic nature, prevention strategies, including genetic counseling and carrier screening, are critical in reducing its prevalence.

Globally, SCD affects millions of people, with the highest prevalence in regions historically affected by malaria, such as Sub-Saharan Africa, India, the Middle East, and parts of the Mediterranean. Approximately 515,000 babies are born annually with SCD worldwide, with Sub-Saharan Africa accounting for the majority of cases. In India, SCD is a significant public health concern, particularly among tribal populations. Over 20 million people in India carry the sickle cell trait, and around 30000 children are born with SCD each year.[2] The prevalence of the sickle cell gene varies across regions, with central and western states such as Maharashtra, Madhya Pradesh, Chhattisgarh, and Odisha being the most affected.[3] Limited access to healthcare, low levels of education, and cultural barriers exacerbate the challenges faced by these populations.

Awareness about SCD prevention among family members of affected children is crucial for breaking the cycle of hereditary transmission. However, studies indicate significant gaps in knowledge regarding the genetic basis of SCD, its inheritance patterns, and preventive measures.[4] Many caregivers are unaware of the importance of genetic counseling, carrier screening, and informed family planning. This lack of awareness often leads to unintentional propagation of the disease through subsequent generations. Prevention in the context of SCD extends beyond genetic counseling and family planning. It includes early detection through newborn screening, timely medical interventions, and lifestyle modifications to reduce complications4.Educating caregivers about these preventive measures is essential for improving the quality of life of affected children and their families.[5]

Studies have shown that informed caregivers are better equipped to navigate the healthcare system, advocate for their child's needs, and create a supportive environment.[6] Despite this, many caregivers lack access to educational resources or live in communities where stigma and misconceptions about genetic diseases prevail. Cultural, social, and economic factors further complicate the awareness and prevention landscape for SCD. In many societies, discussing genetic conditions is fraught with stigma, leading to reluctance among families to seek genetic counseling or disclose their carrier status.[7] Misconceptions about the causes and management of SCD often perpetuate harmful practices, such as reliance on unproven alternative therapies.[8] Economic barriers, including the high cost of genetic testing and limited access to specialized healthcare, also hinder efforts to promote awareness and prevention.[9] Addressing these challenges requires a multi-pronged approach that includes community-based education, affordable healthcare services, and policy-level interventions aimed at reducing the stigma associated.

Despite the extensive research conducted globally and in various parts of India, a critical gap remains in the literature. Specifically, there is a lack of studies focusing on awareness about the prevention of SCD among family members of affected children in Central India. This region, is home to many tribal and underserved communities, where cultural and socio-economic barriers compound the challenges of disease prevention. Understanding this context is essential for designing targeted interventions that can address the unique needs of these populations and help break the cycle of SCD transmission.

The State Haemoglobinopathy Mission was established in Madhya Pradesh to address the challenges associated with the screening and management of sickle cell disease (SCD). As part of this initiative, a pilot project was launched by the Honourable Prime Minister on 15th November 2021, focusing on screening efforts in the Jhabua and Alirajpur districts of Madhya Pradesh. In the second phase of the project, 89 tribal blocks were included to expand the scope of screening. According to state reports, a total of 993,114 individuals have been screened under this mission. Among them, 18,866 individuals were identified as carriers of the sickle cell trait (HbAS), while 1,506 were diagnosed with sickle cell disease (HbSS).[10]

This study aims to evaluate the level of awareness regarding the prevention of SCD among family members of children diagnosed with the condition. The primary objective is to assess their knowledge, attitudes, and practices related to SCD prevention. Additionally, the study seeks to educate and empower family members with information and strategies to actively engage in preventive measures. By focusing on both evaluation and education, this research aspires to bridge existing knowledge deficits and support families in mitigating the impact of SCD.

MATERIALS AND METHODS

This was a hospital-based, observational case-control study conducted in the Department of Paediatrics at a tertiary-care teaching hospital in

Central India. The study was undertaken from 10th October 2023 to 10th October 2024 (12 months).

The study population comprised family members (aged >18 years) of children diagnosed with sickle cell disease (≥2 years after diagnosis) presenting at our center during the study period. Exclusions: <18 years; unwilling to participate; families of children diagnosed within 2 years of start of the study.

Sampling and sample size. A convenience sampling technique was used. The sample size was calculated using Cochran's formula $n=z^2.p.q/d^2$; with Z=1.96, p=50, q=50, d=6.3, yielding ~242 ≈ 240, at 80% power and 5% significance.

All eligible family members were explained about the study in their own language. They were informed that it is a survey type of study based on questionnaire, and that no investigations/tests are conducted for the specific requirement of the study. After written informed consent, participants received the questionnaire and completed it in ~15–20 minutes. After completing the questionnaire, an educational session on prevention of sickle cell disease, including genetic counseling, early diagnosis, and preventive measures, was delivered in a clear and comprehensible manner; participants were encouraged to ask questions for clarification.

A structured questionnaire comprising 20 multiple-choice questions (MCQs) was used to assess awareness and knowledge regarding prevention. The questions were adapted from the International Journal of Community Medicine and Public Health, April 2017.

Information was first recorded in a personalized form and converted to Microsoft Excel for examination. IBM SPSS version 22 was utilized to compute the p values. Descriptive statistics were presented in the form of numbers and percentages.

The protocol was submitted to and reviewed by the Institutional Ethics Committee, and approval was obtained prior to initiation. Voluntary written informed consent was obtained before inclusion; confidentiality was maintained.

RESULTS

A total of 240 family members participated. Most respondents were 21–40 years (56.7%, n=136), followed by 41–60 years (37.5%, n=90), with a smaller proportion >60 years (5.8%, n=14). Females constituted 43.3% (n=104) and males 56.7% (n=136). Socioeconomic status was largely middle/lower: upper class 0.0% (n=0), upper middle 2.5% (n=6), middle 47.1% (n=113), lower middle 19.6% (n=47), and lower 30.8% (n=74). Educational status showed 0.8% graduates (n=2), 4.6% higher secondary (n=11), 13.3% high school (n=32), 43.3% middle school (n=104), 31.7% primary school (n=76), and 6.3% illiterate (n=15). Participants were drawn from multiple districts (e.g., Alirajpur 7.5%, Barwani 7.9%, Dewas 4.6%, Betul 1.7%, Burhanpur 4.6%, Balaghat 0.8%). With respect to caregiving relationship, the majority were parents: fathers 51.7% (n=124), mothers 37.9% (n=91), with grandparents 8.7% (n=21) and other relatives 1.7% (n=4). Familial clustering of disease was present in 17.5% (n=42), while 82.5% (n=198) reported no other affected members.

Regarding causation, "hereditary" was the predominant and presumably correct response (63.3%), while smaller proportions attributed the disease to infection (13.3%), lifestyle (13.3%), and diet (10.0%), indicating persisting misconceptions about etiology. For diagnosis, 56.7% identified "symptoms" and 43.3% identified "blood test"; no respondents chose X-ray or USG, suggesting an awareness that laboratory testing underpins confirmation, although reliance on symptoms remained common. Awareness of sickle cell trait (SCT) was low: only 11.7% had heard of SCT, while 88.3% had not. Consistent with this, most respondents recognized that people with the trait are asymptomatic (85.0% "No symptoms"; 8.3% "Yes"; 6.7% "Don't know").

When asked if a child can have SCA when both parents are carriers, 73.3% answered "Yes" (correct), 10.0% "No," and 16.7% "Don't know". In contrast, a frequent misconception persisted that SCA can occur when only one parent is a carrier—71.7% answered "Yes" (incorrect), whereas 8.3% correctly answered "No" and 20.0% were unsure.

Probability questions further highlighted gaps. For the chance of trait in offspring when both parents are carriers, only 25.0% marked the correct probability (50%), while 65.0% "Don't know," 3.3% chose 25%, and 6.7% chose 100%. For the chance of SCA when both parents are carriers, 10.0% correctly chose 25%, 20.0% chose 50%, 8.3% chose 100%, and 61.7% "Don't know," again indicating substantial uncertainty about Mendelian risk.

Self-testing was uncommon: only 21.7% reported that they had ever been tested for SCT/SCD; 78.3% had not. Testing among siblings/other relatives showed a near-even split (Yes 48.3%, No 50.0%, Don't know 1.7%). In principle, however, most endorsed family-based screening: if a child has SCA, 78.3% agreed parents and siblings should be tested (No 13.3%, Don't know 8.3%). Knowledge of the appropriate test for detecting SCT was suboptimal: only 18.3% identified Hb electrophoresis, 15.0% selected CBC, and two-thirds (66.7%) did not know the test to request.

Three-quarters (75.0%) believed SCA can be prevented/controlled (No 8.3–6.7%; Don't know 16.7–18.3%). Support for premarital screening was strong: 83.3% endorsed getting the partner's Hb electrophoresis done (No 0%, Don't know 16.7%). Most respondents discouraged marriage between two carriers (71.7% opposed; remaining supportive/unsure). Regarding marital possibilities for persons with SCA, 75.0% agreed that individuals with SCA can marry, and when asked about suitable partners, 76.7% preferred a "normal person," with very small proportions favouring a trait partner

(1.7%) or a partner with SCA (3.3%); 18.3% were unsure. Awareness of prenatal screening if both parents are traits was modest: 40.0% "Yes," while "No" and "Don't know" were each 30.0%, reflecting considerable uncertainty about available prenatal options.

Most respondents were parents from lower- and middle-income backgrounds. They generally understood that SCD is hereditary and endorsed prevention through screening and counselling. However, knowledge about the carrier state, the correct test (Hb electrophoresis), and the actual inheritance probabilities was limited. Personal testing was uncommon and testing of other relatives was only moderate, despite broad support for family and premarital screening. Overall, attitudes favored prevention, but this has not yet translated into consistent use of carrier testing or fully informed reproductive choices.

Table 1: Baseline characteristics of respondents (N = 240)

Variable	Category	n	%
Age group (years)	21–40	136	56.7
	41–60	90	37.5
	>60	14	5.8
Sex	Male	136	56.7
	Female	104	43.3
Socioeconomic class	Upper	0	0.0
	Upper-middle	6	2.5
	Middle	113	47.1
	Lower-middle	47	19.6
	Lower	74	30.8
Education	Illiterate	15	6.3
	Primary	76	31.7
	Middle school	104	43.3
	High school	32	13.3
	Higher secondary	11	4.6
	Graduate	2	0.8
Relation to patient	Father	124	51.7
	Mother	91	37.9
	Grandparent	21	8.7
	Other relative	4	1.7
Another affected family member	Yes	42	17.5
	No	198	82.5

Table 1. Baseline characteristics of respondents (N = 240).

Legend: Descriptive profile of respondents by age, sex, socioeconomic class, education, caregiving relationship, and presence of another affected family member. Values are **n (%)**, based on the total sample (N=240). Age groups are mutually exclusive. Socioeconomic class categories are presented as recorded in the study schedule (no reclassification). "Relation to patient" denotes the respondent's caregiving role. "Another affected family member" reflects self-reported presence of other relatives with sickle cell disease. Percentages may not sum to 100 due to rounding. **Abbreviation:** SCD, sickle cell disease.

Table 2: Awareness and knowledge related to SCD prevention (N = 240)

Domain / Item	Response option	n	%
Cause of SCD	Hereditary (correct)	152	63.3
	Infection	32	13.3
	Lifestyle	32	13.3
	Diet	24	10.0
How is SCD diagnosed?	Symptoms	136	56.7
	Blood test	104	43.3
	X-ray / USG	0	0.0
Heard of sickle cell trait (SCT)	Yes	28	11.7
	No	212	88.3
Symptoms in a person with trait	No symptoms	204	85.0
	Yes	20	8.3
	Don't know	16	6.7
Test to detect SCT (carrier test)	Hb electrophoresis (correct)	44	18.3
	CBC	36	15.0
	Don't know	160	66.7
If both parents are carriers – child with trait	Correct probability	60	25.0
If both parents are carriers – child with SCD	Correct probability	24	10.0
Can SCD occur if only one parent is a carrier?	Yes (incorrect)	172	71.7
	No (correct)	20	8.3
	Don't know	48	20.0
Prenatal screening available if both are traits	Yes	96	40.0
	No	72	30.0
	Don't know	72	30.0
SCD can be reduced/controlled by preventive methods	Agree	180	75.0

Table 2. Awareness and knowledge related to SCD prevention (N = 240).
Legend: Items cover cause, diagnostic awareness, trait literacy, knowledge of the correct carrier test, inheritance probabilities when both parents are carriers, awareness of prenatal screening when both partners are traits, and belief that prevention is possible. Values are **n (%)**; single-response multiple-choice unless stated. "Correct" indicates the expected answer per standard SCD genetics/diagnostics (cause: hereditary; diagnostic awareness: blood test; carrier test: hemoglobin electrophoresis; inheritance: 50% child with trait and 25% child with SCD when both parents are carriers). "Symptoms" under diagnosis reflects awareness and does not imply a clinical diagnostic criterion. "Don't know" was an allowed option and is shown where applicable. Percentages may not sum to 100 due to rounding. **Abbreviations:** SCD, sickle cell disease; SCT, sickle cell trait; SCA, sickle cell anaemia; Hb electrophoresis, hemoglobin electrophoresis; CBC, complete blood count; USG, ultrasonography.

Table 3: Testing behaviours and prevention-oriented attitudes (N = 240)

Domain / Item	Response	n	%
Self-testing for SCD/SCT (ever)	Yes	52	21.7
Any other family member tested	Yes	116	48.3
If child has SCA: test parents & siblings	Endorses testing	188	78.3
Premarital screening	Supports (partner Hb electrophoresis)	200	83.3
Marriage between two carriers	Discourages	172	71.7
If person has SCA, preferred partner	Non-trait partner	184	76.7
People with SCA can marry	Agree	180	75.0

Table 3. Testing behaviours and prevention-oriented attitudes (N = 240).
Legend: Summary of self-testing, testing among other relatives, endorsement of testing parents/siblings when a child has SCA, support for premarital screening (partner Hb electrophoresis), stance on marriage between two carriers, preferred partner for a person with SCA, and agreement that individuals with SCA can marry. Values are **n (%)**. "Endorses testing" represents an attitude item (intended practice) rather than observed uptake. Percentages may not sum to 100 due to rounding. **Abbreviations:** SCD, sickle cell disease; SCT, sickle cell trait; SCA, sickle cell anaemia; Hb electrophoresis, hemoglobin electrophoresis.

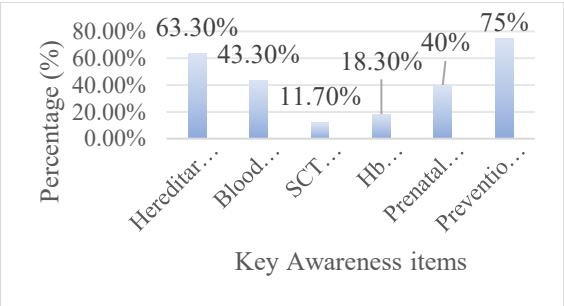

Figure 1: Key Awareness Items about Sickle Cell Disease (%)

Figure 1. Key awareness items about sickle cell disease among family members (N=240).
Bar chart showing the proportion who: identified heredity as the cause, recognized blood tests for diagnosis, had heard of sickle cell trait (SCT), knew hemoglobin electrophoresis is the carrier test, knew prenatal screening is available when both partners are traits, and believed prevention is possible. Values are percentages of respondents.
Abbreviations: SCD = sickle cell disease; SCT = sickle cell trait; Hb electrophoresis = hemoglobin electrophoresis.

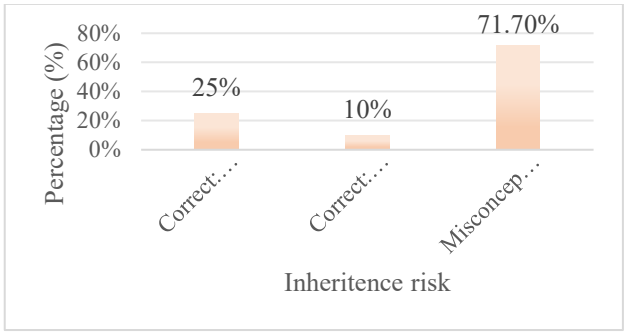

Figure 2: Inheritance Risk Understanding & Misconception

Figure 2. Inheritance risk understanding and misconception (N=240)
Bar chart depicting correct responses for the probability of a child with trait (50%) and with SCD (25%) when both parents are carriers, alongside the common misconception that SCD can occur if only one parent is a carrier. Values are percentages of respondents.
Abbreviations: SCD = sickle cell disease.

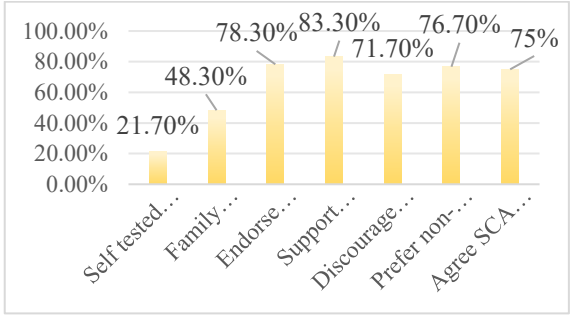

Figure 3: Testing Behaviours and Attitudes

Figure 3. Testing behaviours and prevention-oriented attitudes (N=240).
Bar chart summarizing self-testing and family testing uptake, endorsement of testing parents/siblings, support for premarital screening, attitudes toward marriage between two carriers, preferred partner for a person with SCA, and agreement that individuals with SCA can marry. Values are percentages of respondents.
Abbreviations: SCD = sickle cell disease; SCA = sickle cell anaemia.

DISCUSSION

The demographic profile of the 160 children with SCD shows a significant concentration in the 5–15-year age group (80.7%), with 41.3% aged 5–10 years and 39.4% aged 10–15 years, reflecting the typical age of symptom onset as painful crises and anemia often manifest in early childhood and prompt medical attention; a similar age profile was reported by Kacha et al,[11] and the low proportion over 15 years (4.4%) may reflect transition to adult services or sampling of pediatric clinics, with improved survival also noted by Kilonzi et al.[12] A male predominance (59.4% vs. 40.6%) was observed despite SCD's autosomal recessive inheritance; prior reports attribute such disparities to sociocultural factors and healthcare-seeking patterns for male children (Rautray et al,[13] Abu Ali et al.[14]). Most patients had sickle cell anemia (90.6%) rather than sickle thalassemia (9.4%), consistent with regional genetic epidemiology (Bindhani et al.[15]) Early diagnosis was common (86.3% by age 5), consistent with newborn screening or early symptomatic detection (Hezekiah et al.[16]); later diagnosis (13.8% after 5 years) suggests delays in underserved settings (Aderotoye-Oni et al,[17]). Family size tended to be moderate (78.8% with 1–2 siblings), potentially shaping caregiving dynamics (Figueirêdo et al,[18]). The caste distribution (54.4% General; 30.6% Scheduled Tribes—Bheel/Bhallala) mirrors known community clustering of SCD (Bindhani et al,[15]).

Among family caregivers, most were 21–40 years (56.7%), followed by 41–60 years (37.5%), indicating a predominantly young, economically active caregiving cohort consistent with prior caregiver profiles (Figueirêdo et al,[18]). A slight male predominance (56.7% vs. 43.3%) contrasted with studies reporting mothers as primary caregivers in African contexts (Nsangou et al,[19]); this may reflect Indian gender norms wherein fathers commonly accompany children to clinics (Aderotoye-Oni et al,[17]). Socioeconomically, 47.1% were middle class, 30.8% lower class, and 19.6% lower-middle, pointing to financial constraints similar to those described among SCD families elsewhere (Kilonzi et al,[12]). Educational attainment was modest (43.3% middle school; 31.7% primary; 6.3% illiterate), echoing associations between lower education and limited genotype awareness (Aderotoye-Oni et al,[17]); these factors likely contribute to the knowledge gaps seen in prevention items. Geographically, caregivers were drawn from 29 districts, with higher representation from Dhar (15.4%), Indore (8.3%), and Barwani (7.9%), mirroring known regional and tribal clustering of SCD (Bindhani et al.[15]).

Care relationships were primarily parental: fathers 51.7% and mothers 37.9% (total 89.6%), with additional support from grandparents (8.7%) and other relatives (1.7%). This pattern underscores parents' central role in SCD management (Abu Ali et al,[14]; Namugerwa et al,[20]) and suggests that fathers may undertake public-facing tasks like clinic attendance in this context (Aderotoye-Oni et al,[17]), while extended family networks provide supplementary support (Figueirêdo et al.[18]).

17.5% of families reported another member with SCD, consistent with hereditary patterns and prior Indian data on clustering (Rautray et al,[13]). The 82.5% without another known affected relative may represent isolated cases or under-ascertainment, particularly where access to testing is limited (Aderotoye-Oni et al,[17]; Kilonzi et al,[12]). Multiple affected members likely add emotional and financial strain, in line with reports of economic burden and family conflict among SCD-affected households (Kilonzi et al.[12])

A prominent misconception was that SCA can result when only one parent is a carrier: 71.7% answered "Yes," compared with 8.3% "No" and 20.0% unsure. This concern echoes broader inheritance misunderstandings reported by Adigwe et al,[21] and Havugarurema et al,[22] and likely reflects confusion about Mendelian genetics compounded by lower educational attainment and limited counselling (Rautray et al.[13]).

Diagnostic literacy showed similar gaps. Only 18.3% identified Hb electrophoresis as the carrier (trait) test, 66.7% were unsure, and 15.0% selected CBC, a non-specific test—patterns that parallel limited diagnostic awareness in Tusuubira et al.[23] and constrained carrier-testing knowledge in Kacha et al.[11] This uncertainty plausibly contributes to low testing uptake because families may not know which test to request, a barrier also noted by Aderotoye-Oni et al.[17]

Understanding of inheritance probabilities when both parents are carriers was weak. Only 25.0% marked the correct probability for an offspring with trait (50%), while 65.0% responded "Don't know," with 3.3% choosing 25% and 6.7% choosing 100%, mirroring gaps reported by Havugarurema et al,[22] and Narang et al.[24] For the probability of an offspring with SCA, 10.0% were correct (25%), 61.7% were unsure, and others selected 50% (20.0%) or 100% (8.3%); again, these patterns are consistent with confusion about Mendelian risk and limited counselling exposure (Rautray et al,[13]).

Family members expressed broadly prevention-favourable attitudes: three-quarters believed SCD

can be reduced/controlled through preventive strategies such as genetic counselling, planned screening, and informed family planning, though 8.3% disagreed and 16.7% were unsure, consistent with caregiver orientations reported by Kilonzi et al,[12] Rautray et al,[13] and Hezekiah et al.[16] This orientation coexisted with strong endorsement of family testing—78.3% supported testing of parents and siblings—echoing findings from Hezekiah et al,[16] and the genetic awareness emphasis in Kilonzi et al,[12] and Aderotoye-Oni et al.[17]

Despite this support, key literacy gaps persisted. Only 18.3% correctly identified Hb electrophoresis as the carrier (trait) test, with two-thirds unsure and 15% selecting CBC; similar diagnostic-awareness deficits were noted by Tusuubira et al,[23] and limited carrier-testing knowledge by Kacha et al.[11] This likely contributed to low personal uptake—just 21.7% had ever been tested a mismatch also linked to cost, stigma, and lower education also noted by Kilonzi et al,[11] Aderotoye-Oni et al,[17] and Adigwe et al.[21]

At household level, screening among relatives was only moderate: 48.3% reported siblings/other relatives had been tested while 50.0% had not, paralleling partial diffusion of testing seen by Abd El-Gawad et al,[5] and Tusuubira et al,[23] amidst access and awareness constraints described by Kilonzi et al.[11]

Attitudes to premarital prevention were strongly supportive: 83.3% endorsed premarital screening (partner Hb electrophoresis) when one partner has SCA, aligning with Uche et al,[50] Rautray et al,[13] and Bindhani et al.[15] Furthermore, most respondents (71.7%) opposed marriage between two SCT carriers, indicating awareness of genetic risk, although 23.3% remained unsure—patterns also noted by Bindhani et al,[15] and Tusuubira et al.[23] Awareness of prenatal options was more limited: only 40.0% knew prenatal screening is possible when both parents are carriers, leaving 60.0% either unaware or unsure, consistent with prevention-knowledge gaps summarised by Kilonzi et al,[12] and Narang et al.[24]

This study's strengths include an adequately powered caregiver sample (N=240) recruited across multiple districts in Central India; a prevention-focused instrument (trait literacy, correct test, inheritance probabilities, premarital/prenatal screening) using a standardized 20-item bilingual questionnaire; real-world tertiary-care implementation with trained interviewers, double data entry, and prior IEC approval. However, the single-center, convenience design limits generalizability; the cross-sectional approach cannot capture change over time or the impact of education; self-reported responses and lower literacy may have affected accuracy and comprehension.

CONCLUSION

This study evaluated awareness about SCD prevention among family members of affected children, with a primary focus on knowledge and a secondary focus on education. Awareness was moderate: 63.3% identified SCD as hereditary and 83.3% supported premarital screening. Notable gaps persisted in trait literacy (11.7%), understanding of inheritance probabilities (25% and 10% correct for trait and SCA risks), and knowledge of the correct diagnostic test (18.3% aware of Hb electrophoresis). Low testing uptake (21.7% personal; 48.3% family) further underscores the need for targeted education. Given the cohort's lower educational attainment and socioeconomic constraints, accessible, low-literacy interventions focused on genetic literacy, screening, and counseling are warranted to translate favourable attitudes into informed decisions and improved prevention.

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