

## BRIEF REPORT

# Sickle Cell Disease-Related Stigma: Quantitative Assessment From India

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## ABSTRACT

This multisite cross-sectional study quantitatively assessed stigma related to sickle cell disease (SCD) in India using the Indian Council of Medical Research-SCD Stigma Scale for India among 208 adult patients and 184 caregivers. Approximately 27% of patients and 41% of caregivers reported severe or very severe stigma. ‘Familial & reproductive’, ‘illness burden’ and ‘perceived blame & social judgement’ stigma domains contributed significantly. Ordinal logistic regression analysis identified pain episodes in patients (AOR = 1.199,  $p = 0.013$ ) and caregiver gender (AOR = 0.300,  $p = 0.016$ ) and income (AOR = 0.999,  $p = 0.048$ ) as significant factors associated with stigma severity. The findings underscore a substantial psychosocial burden and highlight the need for culturally grounded, multilevel interventions integrated into SCD care programs to address stigma comprehensively.

## 1 | Introduction

Sickle cell disease (SCD), caused by a missense mutation in the beta-globin gene of haemoglobin, affects populations worldwide, with an estimated 515,000 affected births annually—about 16% of which occur in India [1]. In addition to physical suffering, the patients and their families undergo a lot of burden in different facets of life. They include reduced productivity and income, disrupted education among children and adolescents, diminished quality of life, and, notably, the stigma [2, 3]. The stigma manifests

as discrimination and shame, and that perpetuates a low quality of life and together deters healthcare seeking [4].

Measuring stigma is crucial for understanding its magnitude, nature and drivers, thereby enabling the design of targeted interventions [5, 6]. Estimating the magnitude is crucial for advocacy efforts and allocating resources for public health interventions [6]. Understanding the type and sources of stigma fosters stakeholder engagement, informing policymakers and healthcare providers about the need to integrate stigma-reduction initiatives

**Abbreviations:** AOR, adjusted odds ratio; ICMR, Indian Council of Medical Research; ISSSI, Indian Council of Medical Research-Sickle Cell Disease Stigma Scale for India; ISSSI-Cg, Indian Council of Medical Research-Sickle Cell Disease Stigma Scale for India-Caregiver; ISSSI-Pt, Indian Council of Medical Research-Sickle Cell Disease Stigma Scale for India-Patient; OLR, ordinal logistic regression; PHC, primary health centre; SCD, sickle cell disease.

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**TABLE 1** | Stigma Scores among adults and caregivers of children (< 18 years) with sickle cell disease.

District (state and zone)	Mild no. (%)	Moderate no. (%)	Severe no. (%)	Very severe no. (%)
<b>Adults with sickle cell disease</b>				
Anuppur (Madhya Pradesh, Central India) ( <i>n</i> = 23)	13 (56.5)	10 (43.5)	0 (0.00)	0 (0.00)
Alluri Sitharama Raju (Andhra Pradesh, South India) ( <i>n</i> = 54)	9 (16.7)	19 (35.2)	26 (48.1)	0 (0.00)
Chottaudepur (Gujarat, West India) ( <i>n</i> = 43)	15 (34.9)	20 (46.5)	7 (16.3)	1 (2.3)
Kandhamal (Odisha, East India) ( <i>n</i> = 42)	9 (21.4)	21 (50.0)	10 (23.8)	2 (4.8)
Mysuru (Karnataka, South India) ( <i>n</i> = 42)	4 (9.5)	28 (66.7)	9 (21.4)	1 (2.4)
Udalguri (Assam, North-East India) ( <i>n</i> = 4)	0 (0.00)	4 (100.0)	0 (0.00)	0 (0.00)
Total Sample ( <i>n</i> = 208)	50 (24.0)	102 (49.0)	52 (25.0)	4 (1.9)
<b>Caregivers of children with sickle cell disease</b>				
Anuppur (Madhya Pradesh, Central India) ( <i>n</i> = 23)	8 (34.8)	15 (65.2)	0 (0.00)	0 (0.00)
Alluri Sitharama Raju (Andhra Pradesh, South India) ( <i>n</i> = 39)	5 (12.8)	25 (64.1)	9 (23.1)	0 (0.00)
Chottaudepur (Gujarat, West India) ( <i>n</i> = 24)	6 (25.0)	14 (58.3)	3 (12.5)	1 (4.2)
Kandhamal (Odisha, East India) ( <i>n</i> = 28)	6 (21.4)	16 (57.1)	6 (21.4)	0 (0.00)
Mysuru (Karnataka, South India) ( <i>n</i> = 32)	0 (0.00)	12 (37.5)	19 (59.4)	1 (3.1)
Udalguri (Assam, North-East India) ( <i>n</i> = 38)	0 (0.00)	2 (5.3)	29 (76.3)	7 (18.4)
Total Sample ( <i>n</i> = 184)	25 (13.6)	84 (45.7)	66 (35.9)	9 (4.9)

Note: Scores (total score is 64 for patients and 68 for caregivers). For patients—Mild Stigma: (16–28); Moderate Stigma: (29–40); Severe Stigma: (41–52); Very Severe Stigma: (53–64). For caregivers—Mild Stigma: (17–29); Moderate Stigma: (30–42); Severe Stigma: (43–55); Very Severe Stigma: (56–68).

[6, 7]. Additionally, stigma measurement provides a baseline for evaluating the impact of these initiatives. However, from India, no data and measurement tools are available on SCD-related stigma. Hence, we developed the India-specific scale, the Indian Council of Medical Research (ICMR)-SCD Stigma Scale for India (ISSSI), to measure the stigma faced by patients (ISSSI-Pt) and caregivers (ISSSI-Cg) [8]. The objective of this study was to quantify the burden of SCD-related stigma among patients and caregivers in India using the ISSSI and to examine socio-demographic and clinical factors associated with stigma severity. Additionally, it outlines the initiatives launched in India to reduce stigma as part of the SCD care program. We hypothesised that a substantial proportion of both patients and caregivers would report severe stigma, and that socio-demographic characteristics and clinical factors would be significantly associated with stigma severity.

## 2 | Methods

This study is a multisite, cross-sectional study conducted among a cohort of individuals with SCD and their caregivers from five districts (two primary healthcare centre (PHC) areas in each district) across five states in India. These districts, listed in Table 1, exhibit diversity in terms of culture, socio-economics, demographics, healthcare infrastructure and SCD endemicity [9].

The data for this study were drawn from the cohort of patients identified during our earlier study [10, 11]. During the study, the SCD patients were diagnosed and confirmed by sickle cell solubility test and haemoglobin electrophoresis. We included 129 adult patients and 120 children with SCD and their corresponding

caregivers. Additionally, 79 adult patients and 64 children with SCD were included, as they had been diagnosed by the local primary healthcare system. However, none of the participants declined to participate. All available and willing adults (aged  $\geq 18$  years) and caregivers (usually parents) of children (< 18 years) with SCD were included. Individuals suffering from other morbidities were excluded. Thus, the sample consisted of 208 patients and 184 caregivers of children with SCD. Stigma was measured among patients and caregivers using the ISSSI-Pt and ISSSI-Cg, respectively [8]. In addition, socio-demographic, illness and healthcare-related issues were collected. Data were analysed using SPSS v.26 for descriptive statistics and ordinal logistic regression (OLR) to identify factors associated with stigma. The stigma scores are continuous variables with a range of scores of 16–64 and 17–68, for ISSSI-Pt and ISSSI-Cg, respectively. However, the severity of stigma was graded as mild (16–28 among patients and 17–29 among caregivers), moderate (29–40 among patients and 30–42 among caregivers), severe (41–52 among patients and 43–55 among caregivers) and very severe (53–64 among patients and 56–68 among caregivers). In addition to the overall stigma score, we also calculated the proportionate contribution of each domain by dividing its mean score by the total score for the scale to understand the domains most affected in this sample. This was a descriptive comparison and did not involve recalculating or modifying the validated weights of the ISSSI. For OLR, the categories of ISSSI were used as the dependent variable, and the independent factors included age, gender, education and occupation of patients/caregivers, family type, annual family income, number of illnesses and pain episodes in the last year, hydroxyurea use, and hospitalisation rate. The study protocol was approved by the institutional ethics committees of the five institutes involved in the study.

**TABLE 2** | Sub-scale-wise stigma scores among adults and caregivers of children (< 18 years) with sickle cell disease.

Stigma domain	Alluri Sitharama						Total sample
	Anuppur (Mean ± SD)	Raju (Mean ± SD)	Chottaudepur (Mean ± SD)	Kandhamal (Mean ± SD)	Mysuru (Mean ± SD)	Udalguri (Mean ± SD)	
Adults with sickle cell disease							
Social disclosure stigma	3.48 ± 1.163	4.48 ± 1.820	4.02 ± 1.626	3.48 ± 1.273	3.69 ± 2.332	3.25 ± 1.500	3.89 ± 1.767
Familial & reproductive stigma	8.17 ± 1.825	13.93 ± 2.847	11.67 ± 4.247	12.14 ± 3.461	10.95 ± 3.364	13.75 ± 0.500	11.86 ± 3.686
Interpersonal stigma	5.91 ± 1.730	6.91 ± 2.373	4.86 ± 2.100	6.45 ± 2.559	6.29 ± 1.384	6.50 ± 1.291	6.15 ± 2.209
Illness burden stigma	7.96 ± 2.099	10.26 ± 2.443	10.21 ± 3.420	11.10 ± 2.516	10.71 ± 2.309	10.75 ± 1.258	10.26 ± 2.735
Healthcare interaction stigma	2.04 ± 0.209	2.46 ± 1.041	2.23 ± 0.649	2.43 ± 0.703	6.07 ± 2.608	2.00 ± 0.000	3.08 ± 2.026
Total stigma score	27.57 ± 4.851	38.04 ± 7.420	33.00 ± 9.123	35.60 ± 8.299	37.71 ± 6.586	36.25 ± 3.775	35.25 ± 8.176
Caregivers of children with sickle cell disease							
Perceived blame and social judgement stigma	14.35 ± 2.673	20.62 ± 4.557	16.63 ± 4.726	17.14 ± 4.782	20.34 ± 3.127	24.84 ± 2.520	19.61 ± 5.086
Judgement and dependency stigma	6.17 ± 1.403	4.36 ± 1.495	5.46 ± 2.146	5.29 ± 1.761	8.34 ± 2.238	8.42 ± 1.407	6.40 ± 2.386
Illness burden stigma	8.83 ± 1.723	9.82 ± 2.361	11.75 ± 2.192	10.89 ± 2.780	10.22 ± 2.121	13.03 ± 1.078	10.84 ± 2.481
Healthcare interaction stigma	2.00 ± 0.00	3.15 ± 1.548	2.25 ± 0.676	2.29 ± 0.763	5.84 ± 2.302	4.66 ± 1.632	3.54 ± 2.013
Total stigma score	31.35 ± 4.638	37.95 ± 6.517	36.08 ± 8.418	35.61 ± 8.167	44.75 ± 6.185	50.95 ± 5.056	40.39 ± 9.260

Abbreviation: SD: standard deviation.

### 3 | Results

The socio-demographic and SCD-related characteristics of adult patients, children with SCD and their corresponding caregivers are given in Table S1. The distribution of categories of stigma indicated that approximately half of the patients (49%) and caregivers (45.7%) reported moderate stigma, while about 27% of patients and 41% of caregivers had severe or very severe scores on the ISSSI (Table 1). The mean scores of different categories of stigma are shown in Table 2. Among the five stigma domains assessed, 'familial & reproductive stigma' and 'illness burden stigma' were the major contributors among patients. Although ISSSI-Pt's theoretical domain weights for the above domains were 31.25% and 25%, in our sample, relatively higher contributions from these domains (33.65% and 29.11%, respectively) were reported. For caregivers, the leading domains were 'perceived blame & social Judgement stigma' and 'illness burden stigma', with assigned theoretical domain weights of 47.06% and 23.53%; however, in our sample, the slightly higher contributions of 48.5% and 26.8%, respectively, were reported.

The OLR indicated that among the patients, most socio-demographic and clinical factors showed no significant asso-

ciation with stigma severity (Table 3). Among patients, the number of pain episodes was marginally associated (AOR = 1.199, 95% CI 1.039–1.384,  $p = 0.013$ ), suggesting that pain episodes among patients were significantly associated with higher stigma severity. The model shows a good fit ( $\chi^2 = 28.888$ ,  $p < 0.004$ ), and Nagelkerke  $R^2$  (0.228) indicated that the model explained 23% of the variance. Among caregivers, male caregivers had 70% lower odds of reporting higher stigma compared to female caregivers (AOR = 0.300, 95% CI 0.113–0.796,  $p = 0.016$ ). And lower annual family income was significantly associated with higher stigma, though the effect per INR is tiny (AOR = 0.999, 95% CI 0.999–1.000,  $p = 0.048$ ). The  $\chi^2$  (38.344,  $p = 0.000$ ) and Nagelkerke  $R^2$  (0.325) indicated that the model is fit, and it explained 32.5% of the variance.

### 4 | Discussion

The present study provides evidence from India on the burden and associated factors of SCD-related stigma. Although our qualitative study reported stigma and discrimination in communities [12], we could measure it quantitatively using ISSSI [8]. Notably, about 27% of patients and 41% of caregivers reported

**TABLE 3** | Details of ordinal logistic regression for the association between stigma categories and adult patients'/caregivers' characteristics.

Variables	Ordinal logistic regression results	
	AOR (95% CI)	<i>p</i>
<b>Patients</b>		
Age	0.974 (0.945–1.000)	0.080
Gender		
Male	0.560 (0.261–1.198)	0.135
Female	Reference	
Education	0.981 (0.882–1.091)	0.732
Occupation		
Agriculture/agriculture labour/gathering and hunting	1.729 (0.608–4.917)	0.305
Paid job	1.092 (0.382–3.121)	0.870
Homemaker	1.203 (0.471–3.072)	0.700
Students/presently not working	Reference	
Family type		
Nuclear family	0.901 (0.396–2.050)	0.803
Joint family	Reference	
Annual income	1.000 (0.999–1.000)	0.115
Illness episodes	0.927 (0.815–1.055)	0.252
Pain episodes	<b>1.199 (1.039–1.384)</b>	<b>0.013</b>
Hospitalisation during the year		
Yes	0.629 (0.266–1.487)	0.291
No	Reference	
Hydroxyurea use	1.025 (0.983–1.070)	0.246
<b>Caregivers</b>		
Patient's age	0.995 (0.737–1.341)	0.972
Caregiver's age	0.995 (0.938–1.056)	0.879
Patient's education	0.874 (0.633–1.208)	0.415
Caregiver's education	1.043 (0.950–1.144)	0.375
Patient's gender		
Male	1.056 (0.469–2.379)	0.895
Female	Reference	
Caregiver's gender		
Male	<b>0.300 (0.113–0.796)</b>	<b>0.016</b>
Female	Reference	
Caregiver's occupation		
Agriculture/agriculture labour/gathering and hunting	1.181 (0.515–2.708)	0.694
Paid job	Reference	
Family type		
Nuclear family	0.705 (0.276–1.801)	0.465

(Continues)

**TABLE 3** | (Continued)

Variables	Ordinal logistic regression results	
Joint family	Reference	
Annual family income (INR)	<b>0.999 (0.999–1.000)</b>	<b>0.048</b>
Illness episodes	1.254 (0.967–1.626)	0.088
Pain episodes	0.876 (0.626–1.226)	0.440
Hospitalisation		
Yes	0.763 (0.249–2.334)	0.635
No	Reference	
Hydroxyurea use	0.983 (0.933–1.037)	0.530

Note: Significance of bold is  $p < 0.05$ . For the model of patients:  $\chi^2$  for model fit = 28.888,  $p < 0.004$ ; Nagelkerke  $R^2 = 0.228$ . For the model of caregivers:  $\chi^2$  for model fit = 38.344,  $p < 0.001$ ; Nagelkerke  $R^2 = 0.325$ .

Abbreviations: AOR, adjusted odds ratio; CI, confidence intervals; INR, Indian National Rupee (Approximately 1INR = 0.01 US\$).

severe and very severe stigma, signalling substantial psychosocial vulnerability. The findings underscore the multidimensionality of SCD-related stigma, with elevated scores in internalised stigma (as measured by domains of 'familial & reproductive stigma', and 'illness burden stigma' of ISSSI-Pt and ISSSI-Cg), social disclosure (as reflected in 'social disclosure stigma' domain of ISSSI-Pt and 'Judgement and dependency stigma' domain of ISSSI-Cg) and perceived discrimination (as measured by 'interpersonal stigma' domain of ISSSI-Pt and 'perceived blame and social judgement stigma' domain of ISSSI-Cg), reflecting entrenched psychosocial burden. Conversely, healthcare interaction stigma was consistently lower, possibly due to the limited interaction of patients and caregivers with healthcare providers. Most findings align with those in other endemic regions, where social isolation and self-stigma are central issues [3, 13]. Studies from the United States, Nigeria and Ghana consistently report significant stigma in SCD, mainly internalised stigma, expected discrimination and social exclusion. In these countries, stigma stems from misconceptions, lack of public awareness and healthcare provider bias, especially during pain-related care seeking [3, 7, 14, 15]. US studies highlight stigma from the public and providers as a major factor affecting mental health and healthcare use [7, 16]. While stigma is higher in Nigeria and Ghana, US patients more often report provider-based discrimination [7, 16]. These variations likely reflect socio-economic, cultural, healthcare and disease-related differences, underscoring the need for multilevel interventions targeting both internalised stigma and systemic discrimination.

The Indian government has recently launched a program to eliminate SCD by 2047 [17]. Subsequently, the screening activities are intensified. The component of care and psychosocial support is included in the program, but it is still at a nascent stage. As diagnoses and healthcare interactions increase, stigma—especially healthcare interaction stigma, currently low—may rise, as observed in the United States [7]. In India, SCD is more prevalent in tribal populations, who are more vulnerable, like the US Black individuals [18]. In this context, ICMR is piloting a multicomponent intervention across 10 PHC areas in five states,

targeting individuals, families, communities and the healthcare system [19]. The strategies include provider training, community mobilisation, peer support, counselling and school-based awareness. The intervention's strength lies in its culturally grounded, participatory approach and its integration into existing health systems for sustainability. Our findings can inform national policies by highlighting the need to integrate stigma-reduction components within the government's SCD elimination program, including structured counselling services, routine provider sensitisation and school-based awareness modules. Engagement of diverse stakeholders—government health agencies, civil society, tribal leaders and patient advocacy groups—will be critical to ensure that stigma reduction is embedded into programmatic guidelines, supported by adequate resources, and sustained through community ownership.

In conclusion, the study provides a quantitative assessment of stigma related to SCD in India and identifies associated factors. The findings reveal a substantial burden of stigma, emphasising the need for psychosocial support in comprehensive care. Policymakers should adopt culturally sensitive, multilevel strategies to address stigma as a key barrier to well-being in SCD. The study has limitations, including its focus on five tribal-dominated districts, which may not represent all tribal areas of the country. Its cross-sectional design prevents establishing causal relationships. Additionally, the stigma was measured through self-report; therefore, the possibility of bias cannot be ruled out.

#### Author Contributions

Conceptualisation and funding acquisition: Bontha V. Babu. Data collection: Parikpandla Sridevi, Shaily B. Surti, Madhusmita Bal, Deepa Bhat, Jatin Sarmah and Manoranjan Ranjit. Data curation, visualisation and analysis: Yogita Sharma, Parikpandla Sridevi, Shaily B. Surti, Madhusmita Bal, Deepa Bhat, Jatin Sarmah, Manoranjan Ranjit and Rabindra K. Jena. Investigation, supervision and project administration: Bontha V. Babu, Yogita Sharma, Parikpandla Sridevi, Shaily B. Surti, Madhusmita Bal, Deepa Bhat, Jatin Sarmah and Manoranjan Ranjit. Writing original draft: Bontha V. Babu and Yogita Sharma. Data were accessed and verified by Yogita Sharma, Parikpandla Sridevi, Shaily B. Surti, Madhusmita Bal, Deepa Bhat, Jatin Sarmah and Manoranjan Ranjit. All authors reviewed the manuscript, provided critical inputs and approved the final manuscript. The decision to submit this manuscript was made by all authors.

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#### Conflicts of Interest

The authors declare no conflicts of interest.

#### Data Availability Statement

The data that support the findings of this study are available upon request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

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### Supporting Information

Additional supporting information can be found online in the Supporting Information section.

**Supplemental Table S1:** Demographic characteristics of participants.