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Clinical, Humanistic and Healthcare Resource Utilization Burden of Sickle Cell Disease in India: Insights from the ASCRIBE Study

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265 PwSCD consulting

32 participating physicians in India

Key results

- **97%** Received hydroxyurea among PwSCD receiving treatment (*n=253/260*)
- **81%** Experienced ≥1 VOC (*n=215/265*)
- **53%** Had ≥2 hospitalizations in the past year (*n=140/264*)

Despite widespread hydroxyurea use, vaso-occlusive crises (VOCs) remained a major unmet need, accounting for 91% of hospitalizations

INTRODUCTION

- Sickle cell disease (SCD) is a major public health challenge in India, accounting for 16% of global annual births with SCD (82,500/515,000).[1,2] As of 28 August 2026, the National Sickle Cell Anemia Elimination Mission dashboard reported more than 72.9 million screenings and approximately 2,50,000 people identified with SCD.[3]
- Despite high burden, contemporary country-specific evidence characterizing SCD's multidimensional impact on patients, caregivers and healthcare systems remains limited.

OBJECTIVE

- The Analysis of Sickle Cell disease Real-world Impact and BurdEn (ASCRIBE) study characterized the clinical, humanistic and healthcare resource utilization (HCRU) burden of SCD in India.

METHODS

- ASCRIBE was a cross-sectional survey based on the Adelphi SCD Disease Specific Programme™ and included retrospective data collected from physicians, people with SCD (PwSCD) and caregivers in India between November 2024 to January 2025. The Disease Specific Programme™ methodology has previously been described, validated, and demonstrated to be consistent over time.[4-7]

1 Eligibility criteria

Physician inclusion criteria
- Relevant SCD specialty or primary care physician
- Treating ≥5 PwSCD/month

Patient inclusion criteria
- Age ≥2 years
- Confirmed SCD diagnosis

2 Physician-reported data

Physician survey (n=32 physicians)
- Physician perceptions (~15 min)

Patient record forms (n=265 PwSCD)
- Prospectively completed by physicians on demographics, clinical characteristics and treatment patterns
- Online after consultation (~25 min) for their next 1–15 eligible patients

3 Patient- and caregiver- reported data

Voluntary self-completion questionnaires (*consent obtained*)
- Completed by adult PwSCD (≥18 years; n=81) and caregivers (n=77) following consultation
- Outcomes assessed: Patient-Reported Outcomes Measurement Information System (PROMIS)-Pain Intensity, Functional Assessment of Chronic Illness Therapy (FACIT)-Fatigue Scale, Burden Scale for Family Caregivers (BSFC)

4 Outcomes assessed and data analysis

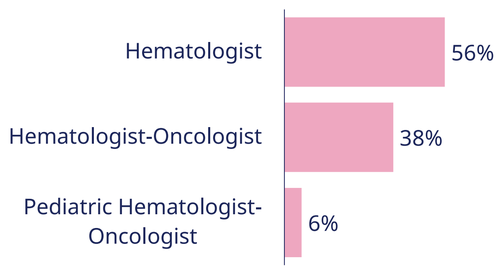
Data were summarized descriptively to characterize the following:
- Clinical characteristics
- Treatment patterns
- Healthcare resource utilization
- Patient-reported outcomes
- Caregiver burden

Note: Missing data were not imputed; analyses were based on available data for each variable and denominators may vary accordingly.

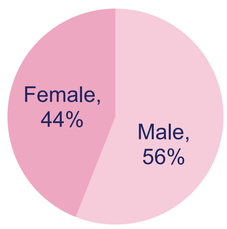
RESULTS

Demographics and treatment pattern: Overall, 32 physicians provided data for 265 PwSCD

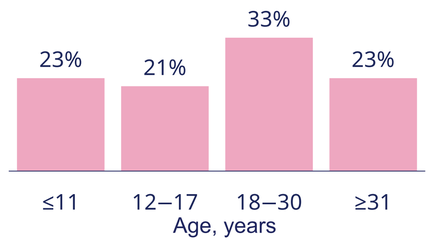
Physician Specialty (n=32)



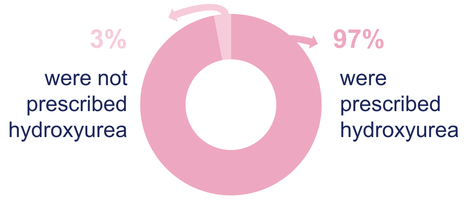
PwSCD Gender (n=265)



PwSCD Age (n=265)
Mean age (SD): 21.4 (12.1)

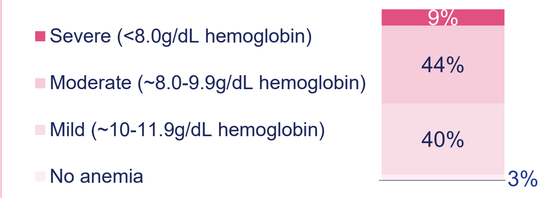


Treatment status at time of survey completion (n=260)*



**Among PwSCD who were receiving treatment for SCD at the time of survey.*

Anemia at time of survey completion* (n=265)



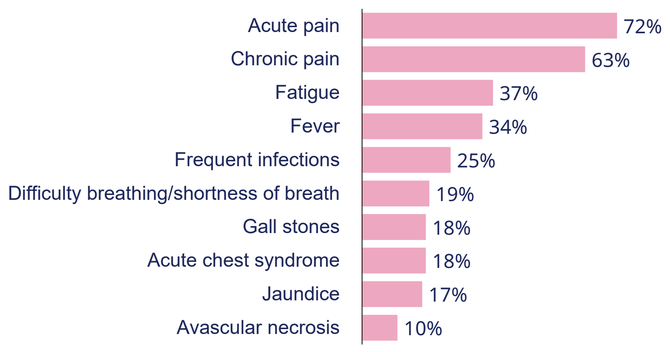
**5% of physicians responded "Don't know."*

- Around three-quarters of PwSCD (75%) had HbSS/HbSβ0 genotype. Most PwSCD (n=260/265) were receiving treatment at time of survey; among those receiving treatment, hydroxyurea (97%) and pain relief medications* (85%) were most common.

**Pain relief medications included acetaminophen, nonsteroidal anti-inflammatory drugs, topical medications, weak opioids, strong opioids, cannabis and others.*

Clinical and healthcare resource burden among PwSCD

Top 10 physician-recorded SCD manifestations at time of survey



- Overall, 95% (n=252/265) of PwSCD experienced at least one SCD manifestation; acute pain (72%) and chronic pain (63%) were the most commonly physician-recorded manifestations.
- Additionally, 38% of PwSCD experienced organ complications.*

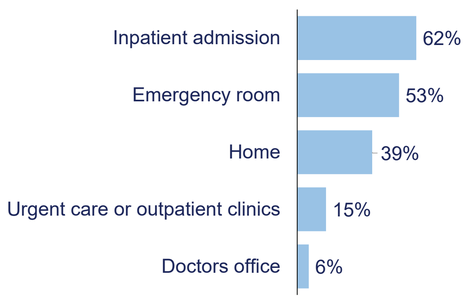
**Organ complications: Avascular necrosis, gall stones, hepatic sequestration, kidney complications, liver failure, retinopathy, splenic sequestration, stroke/transient ischemic attack/cerebral infarcts, pulmonary hypertension, acute chest syndrome.*

VOC-related burden in the past year (n=265)

81% experienced ≥1 VOC

Mean (SD)
2.6 (1.8)
VOCs among PwSCD experiencing ≥1 VOC

VOC management settings* among PwSCD with ≥1 VOC (n=215)



- Among PwSCD with ≥1 VOC (n=215), VOCs were most frequently managed in inpatient settings (62%) and emergency room (53%).
- In the past year, 33% (88/265) of all PwSCD experienced ≥3 VOCs.

**Multiple settings could be reported.*

Hospitalizations in the past year (n=264)

80% were hospitalized

Mean length of stay per hospitalisation: 7.1 nights (SD 5.5; n=192)

91% of these were VOC-driven

Blood transfusions in the past year (n=262)

48% received ≥1 blood transfusion

Mean number of transfusions recipients: 3.3 (SD 3.0; n=126)

- Among PwSCD with ≥1 hospitalization (n=211), 91% of hospitalizations were VOC-driven, 89% were via emergency departments (available data n=210) and 17% received intensive care (available data n=210).
- In the past year, 53% (140/264) of PwSCD had ≥2 hospitalizations.

Humanistic burden: Patient- and caregiver-reported burden via voluntary, self-completed questionnaires

Patient-reported outcomes (N=81)

A. Pain intensity (PROMIS*)

59.5 (8.3) Mean (SD) PROMIS Pain Intensity (US population norms=50.0)

B. Fatigue (FACIT-Fatigue)**

26.6 (8.5) Mean (SD) FACIT-Fatigue (Significant fatigue threshold <34.0[8])

**The PROMIS Pain Intensity 3a assesses pain over the past 7 days using self-reported ratings of pain intensity at is worst and on average, including the level of pain being experienced at time of form completion. Higher score indicates greater pain intensity.*
***The Functional Assessment of Chronic Illness Therapy – Fatigue Scale (FACIT-Fatigue) is a 13-item measure that assesses self-reported fatigue and its impact upon daily activities and function. The highest possible score is 52. A higher FACIT-Fatigue score indicates less fatigue. Cut off threshold for significant fatigue <34.0.*

Caregiver outcomes (N=77)

A. Time spent providing care (n=73/77)

55.3 (37.8) Mean (SD) hours of care provided per week

B. Caregiver-reported burden (BSFC*) (n=74/77)

15.1 (3.7) Mean (SD) BSFC (Severe burden range 15-30)

**The Burden Scale for Family Caregivers (BSFC) score is 10 item multi-choice tool where respondents rate on a 4-point Likert scale from strongly disagree to strongly agree. This tool is used to measure perceived burden resulting from home care experienced by caregivers. A score of 15-30 represents severe to very severe burden.*

CONCLUSIONS

- Among PwSCD consulting participating physicians in India, substantial clinical, patient-reported, caregiver and HCRU burden was observed with high VOC-related hospitalizations despite widespread hydroxyurea use. These findings provide India-specific real-world evidence that may inform health-service planning and future health technology assessment evidence generation.

References: 1. Rahiman EA, et al. *Int J Neonatal Screen*. 2026;12(1):10. 2. GBD 2021 Sickle Cell Disease Collaborators. Lancet Haematol. 2023;10(8):e585-e599. 3. National Health Mission. National Sickle Cell Anaemia Elimination Mission Dashboard. Available from: https://sickle.nhm.gov.in/home/guest_dashboard. Accessed August 28, 2026. 4. Anderson P, et al. *Curr Med Res Opin*. 2008;24:3063-72. 5. Anderson P, et al. *Curr Med Res Opin*. 2023;39:1707-15. 6. Babineaux SM, et al. *BMJ Open*. 2016;6:e010352. 7. Higgins V, et al. *Diabetes Metab Syndr Obes*. 2016;9:371-80. 8. Cheminet G, et al. *Br J Haematol*. 2024;205:335-42. **Funding:** This analysis was fully funded by Novo Nordisk Healthcare AG, Switzerland and used data from the Adelphi sickle cell disease (SCD) Disease Specific Programme™ dataset which is an independent data source and wholly owned by Adelphi Real World. **Disclosure**: Dr Manisha Madkaikar has no relevant conflicts. At the time of study conduct, authors were part of their respective affiliations listed. **Acknowledgements:** The authors thank Kim Brown and Johan Cherian from Novo Nordisk Health Care for their critical review of the poster. The authors also thank Parinita S and Jims Jacob from Novo Nordisk GBS, Bangalore, India, for their medical writing and graphic design support, respectively.
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