P1487

# Sickle Cell Health Awareness, Perspectives and Experiences (SHAPE) Survey: Findings on the Burden of Sickle Cell Disease on Patients and Their Unmet Needs As Reported by Healthcare Professionals

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## BACKGROUND

- Sickle cell disease (SCD) places a substantial emotional and physical burden on patients as well as their caregivers; currently, there is limited research on the impact of SCD on patient and caregiver quality of life (QOL).[1,2]
- Improving patient QOL remains an important treatment goal.[1,3]
- To complement this drive to improve patient QOL, a more detailed understanding of what it means to live with and receive care for SCD in different communities is needed, especially considering the health inequalities faced by different groups around the world.[1,4]
- Insights from healthcare professionals (HCPs) are important because HCP perspectives may reflect and complement perspectives on patient and caregiver QOL.

## OBJECTIVE

- To understand HCP perspectives on the patient burden of SCD, the impact of SCD on patient QOL, and the needs of patients with SCD.

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## METHODS

- The SHAPE survey is a multinational study composed of quantitative online surveys of patients, caregivers, and HCPs that aims to broaden the understanding of the impact of SCD and patients' unmet needs, highlight healthcare inequalities, and increase disease awareness.
- The survey was conducted in 10 countries: France, Germany, United Kingdom, United States, Canada, Brazil, Saudi Arabia, United Arab Emirates, Bahrain, and Oman (patients only).
- The surveys required participants to answer a range of closed-ended questions about their circumstances and experiences in order to build a robust and reliable data set on which descriptive statistics were performed.
- Informed consent was obtained from all participants, all identifiable information was kept private and secure, and the study protocol was reviewed and approved by an independent institutional review board.
- This analysis focuses on findings from the HCP survey portion of the study.
  - HCPs were included if they had at least 10 patients with SCD under their care and had been practicing for 3 to 35 years.

## RESULTS

### HCP Demographic Information

- A total of 219 HCPs representing various countries, specialties, practice sizes, and patient age groups treated were interviewed (**Figure 1**).

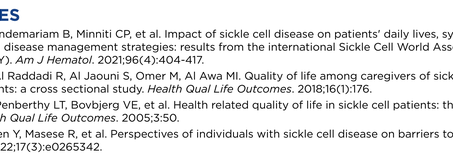
#### Figure 1. HCP Demographic Information

A.

| HCPs | United States | Germany | Brazil | France | United Kingdom | Canada | Saudi Arabia | United Arab Emirates | Total |
|---|---|---|---|---|---|---|---|---|---|
| n (%) | 50 (23) | 33 (15) | 31 (14) | 30 (14) | 30 (14) | 15 (7) | 15 (7) | 15 (7) | **219** |

B.


C.




D.




GCC, Gulf Cooperation Council; HCP, healthcare professional; SCD, sickle cell disease.

### HCPs' Relationship With Their Patients

- Nearly 1 in 3 HCPs (31%) found it challenging to understand their patients' needs, with more than 2 in 5 (43%) citing difficulties due to having different ethnic backgrounds from their patients (**Figure 2**).

#### Figure 2. Percentage of HCPs Who Agreed[a] With the Following Statements on Their Relationship With Their Patients




[a]Percentages reflect HCPs who answered "somewhat agree" or "strongly agree" to this statement.
HCP, healthcare professional; SCD, sickle cell disease.

### Patient Symptoms

- HCPs believed their patients were most impacted by fatigue/tiredness, vaso-occlusive crisis pain, and bone aches (**Table 1**).

#### Table 1. Most Common Symptoms Reported by Patients With SCD by Age Group[a]

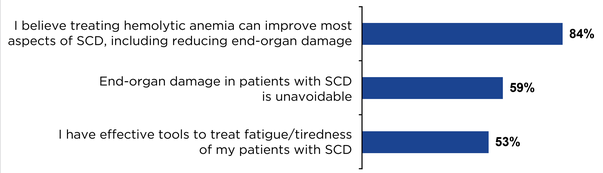
| | Patients aged ≤11 years | Patients aged 12-17 years | Patients aged ≥18 years |
|---|---|---|---|
| **1st** | VOC pain (n=72, 63%) | Fatigue/tiredness (n=108, 68%) | Fatigue/tiredness (n=158, 76%) |
| **2nd** | Bone aches (n=66, 58%) | VOC pain (n=99, 63%) | VOC pain (n=151, 73%) |
| **3rd** | Fatigue/tiredness (n=64, 56%) | Bone aches (n=90, 57%) | Bone aches (n=135, 65%) |

[a]Base number of respondents: patients aged ≤11 years, n=114; patients aged 12-17 years, n=158; patients aged ≥18 years, n=208. Symptoms were reported to HCPs during routine office visits. More than 1 symptom could be selected by HCPs.
HCP, healthcare professional; SCD, sickle cell disease; VOC, vaso-occlusive crisis.

### Treatment of SCD

- Most HCPs (84%) believed that treating hemolytic anemia can improve most aspects of SCD, including reducing end-organ damage, but almost two-thirds (59%) of HCPs believed that end-organ damage is unavoidable (**Figure 3**).
- Although fatigue/tiredness has one of the biggest impacts on patients' lives, only half (53%) of HCPs felt they have effective tools to treat this symptom.

#### Figure 3. Percentage of HCPs Who Agreed[a] With the Following Statements on SCD Treatment

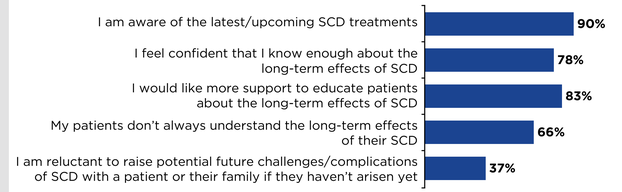



[a]Percentages reflect HCPs who answered "somewhat agree" or "strongly agree" to the statement.
HCP, healthcare professional; SCD, sickle cell disease.

### HCP and Patient Education

- Most HCPs (78%) felt confident in their knowledge of the long-term effects of SCD, but 83% wanted more support in educating their patients on this topic (**Figure 4**).
- Two-thirds (66%) of HCPs felt that their patients do not always understand the long-term effects of their SCD, and more than one-third (37%) were reluctant to raise potential future challenges or complications with a patient or their family.

#### Figure 4. Percentage of HCPs Who Agreed[a] With the Following Statements Related to HCP and Patient Education




[a]Percentages reflect HCPs who answered "somewhat agree" or "strongly agree" to this statement.
HCP, healthcare professional; SCD, sickle cell disease.

### Impact of SCD on Patients' QOL

- Almost two-thirds of HCPs believed that SCD greatly affects patients' long-term health prospects (64% for patients aged <18 years; 60% for patients aged ≥18 years) and their ability to attend and succeed at school or work (53% for <18 years; 49% for ≥18 years; **Figure 5**).

#### Figure 5. Percentage of HCPs Who Believed SCD Greatly Impacts Patients' Lives in the Following Areas




### Financial Burden of SCD on Patients

- Most HCPs (82%) agreed that SCD causes financial difficulties for patients and that cost factors into their decision to recommend a treatment (64%; **Figure 6**).

#### Figure 6. Percentage of HCPs Who Agreed[a] With the Following Statements on the Financial Burden of SCD




[a]Percentages reflect HCPs who answered "somewhat agree" or "strongly agree" to this statement.
HCP, healthcare professional; SCD, sickle cell disease.

## CONCLUSIONS

- Fatigue/tiredness has one of the biggest impacts on patients' lives, and HCPs reported a need for effective tools to treat this symptom.
- HCPs noted an unmet need for treatments that fully address end-organ damage in SCD and reported the great impact SCD has on multiple aspects of patients' lives.
- Almost one-third of HCPs found it challenging to understand their patients' needs, suggesting that additional support for HCPs in their communication with and education of their patients could result in more-effective SCD treatment.
- Responses from HCPs suggest that patients with SCD and their caregivers face financial difficulties, which may consequently affect their access to care and result in discrepancies in education about their disease.
- These findings highlight the complex environment that HCPs face when treating patients with SCD, including differences in socioeconomic status and ethnic background, the need for education, and a lack of resources.

## REFERENCES

1. Osunkwo I, Andemariam B, Minniti CP, et al. Impact of sickle cell disease on patients' daily lives, symptoms reported, and disease management strategies: results from the international Sickle Cell World Assessment Survey (SWAY). *Am J Hematol*. 2021;96(4):404-417.
2. Madani BM, Al Raddadi R, Al Jaouni S, Omer M, Al Awa MI. Quality of life among caregivers of sickle cell disease patients: a cross sectional study. *Health Qual Life Outcomes*. 2018;16(1):176.
3. McClish DK, Penberthy LT, Bovbjerg VE, et al. Health related quality of life in sickle cell patients: the PiSCES project. *Health Qual Life Outcomes*. 2005;3:50.
4. Phillips S, Chen Y, Masese R, et al. Perspectives of individuals with sickle cell disease on barriers to care. *PLoS One*. 2022;17(3):e0265342.

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## DISCLOSURES

- **Mariane de Montalembert:** Consultant: Addmedica, Novartis, Bluebird Bio, Vertex. **Alan Anderson:** Consultant: Global Blood Therapeutics; research support: Global Blood Therapeutics; advisory board: Vertex Pharmaceuticals, Forma Therapeutics. **Fernando F. Costa:** Consultant: Novartis. **Wasil Jastaniah:** Consultant, honoraria: Novartis, Amgen, Bayer. **Joachim B. Kunz:** Consultant: Novartis, Global Blood Therapeutics, Bluebird Bio. **Isaac Odame:** Consultant: Novartis, Novo Nordisk; honorarium: Global Blood Therapeutics. **Anne Beaubrun:** Employee, equity ownership: Global Blood Therapeutics. **Belinda Lartey:** Employee: Ipsos Healthcare. **Baba P. D. Inusa:** Educational funding: Global Blood Therapeutics, Celgene, Novartis Pharmaceuticals, AstraZeneca, Bluebird Bio; honoraria: Global Blood Therapeutics, Novartis Pharmaceuticals, Cyclerion, Forma Therapeutics, Agios, Nova.
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