

## **Sickle Cell Health Awareness, Perspectives and Experiences (SHAPE) Survey: Findings on the Burden of Sickle Cell Disease and Unmet Needs as Reported by Patients and Caregivers**

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**Background/Introduction:** Sickle cell disease (SCD) has a substantial emotional and physical burden on patients and their caregivers. Research on the impact of SCD on patient and caregiver quality of life (QOL) is limited, including on the health inequalities faced by different groups around the world. The limitations in research underscore the need for greater understanding of the challenges of living with SCD in different communities. The SHAPE survey aims to broaden the understanding of the global impact of SCD on patients living with the condition, on caregivers caring for those living with the condition, and on healthcare professionals (HCPs) who treat SCD.

**Materials and Methods:** The SHAPE survey comprised online, quantitative surveys of patients, caregivers, and HCPs conducted in 10 countries: France, Germany, UK, US, 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 dataset on which descriptive statistics were performed. This analysis focuses on findings from the patient and caregiver survey portion of the study. Patients were included if they were diagnosed with SCD by an HCP and were aged  $\geq 12$  years. Caregivers were included if they were caring for someone diagnosed with SCD and were aged  $\geq 18$  years. Informed consent was obtained from all participants, and all identifiable information was kept private and secure. The study protocol was reviewed and approved by an independent institutional review board.

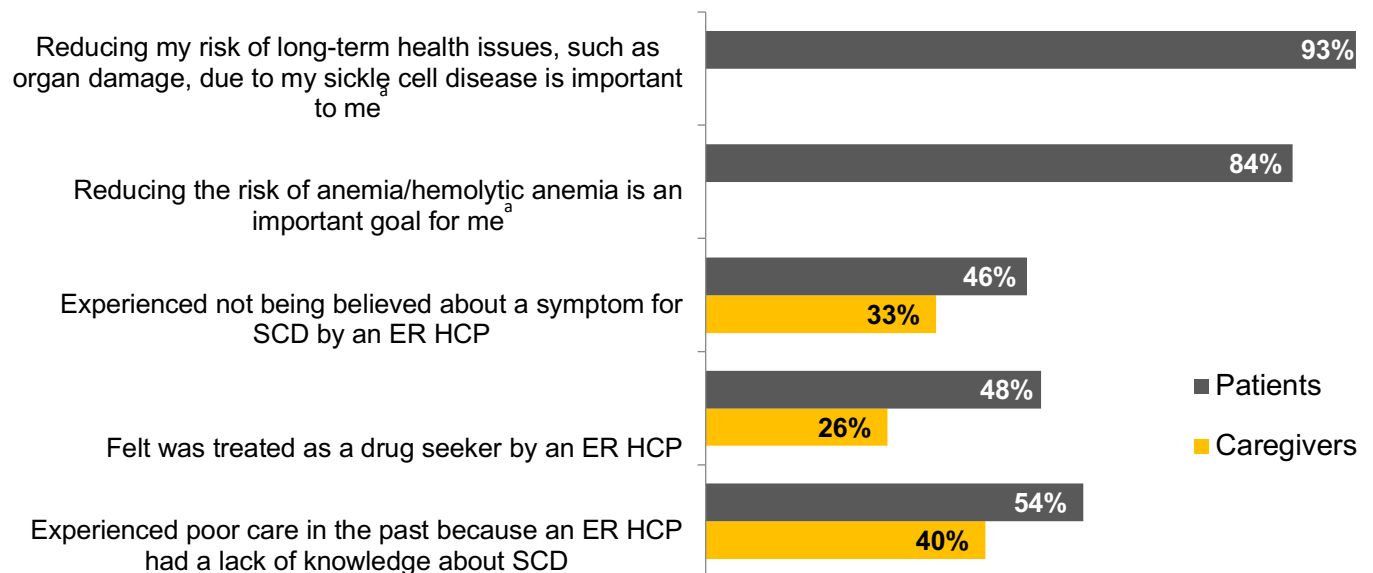
**Results:** A total of 919 patients and 207 caregivers completed the survey. The mean patient age was 32.3 years, and most patients and caregivers were female. Nearly all patients stated that reducing the risk of long-term complications, such as organ damage (93%) and hemolytic anemia (84%), was important to them (Figure). Caregivers felt that most areas of their lives—particularly their ability to attend and succeed at school or work (56%) and their own overall wellbeing (53%) and mental health (52%)—were impacted by caring for someone with SCD. The symptom experienced by patients with SCD that most impacted caregivers' lives was fatigue/tiredness (49%), and 54% of caregivers reported a notable impact on their earning potential. Those caring for patients aged  $< 18$  years were more likely to have their ability to attend and succeed at school or work impacted than those caring for patients aged  $\geq 18$  years (61% vs 38%, respectively). A total

of 46% of patients and 33% of caregivers reported that emergency room (ER) HCPs did not believe patients about their symptoms, and 48% of patients felt they were treated as a drug seeker by ER HCPs. Similarly, 54% of patients and 40% of caregivers reported ER HCPs provided poor care due to their lack of knowledge about SCD.

**Discussion/Conclusion:** The experience of a global group of patients with SCD shows that what most impacted caregivers' lives was fatigue/tiredness and loss of earnings and this provides insight on the broad impacts of SCD and highlights areas that need greater support or improvement.

**Table/Figure:**

**Figure: Percentage of Patients or Caregivers Who Agreed<sup>a</sup> With or Endorsed the Following Statements**



<sup>a</sup>Percentages reflect patients and caregivers who answered “somewhat agree” or “strongly agree” to this statement.

ER, emergency department; HCP, healthcare professional; SCD, sickle cell disease.

**Disclosures:**

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