The Sickle Cell World Assessment Survey (SWAY)

An international, multicountry, cross-sectional survey assessing the impact of sickle cell disease (SCD) on the daily life of patients, including:

- **Physical Symptoms**
- **Emotional Well-being**
- **Economic Burden**

Vaso-occlusive crises (VOCs) and Hospitalizations

Patients who completed the survey reported substantially higher numbers of VOCs than current published data, suggesting VOCs are underreported.

- Of patients surveyed experienced at least 1 VOC in the past 12 months and 39% experienced 5 or more VOCs during their time.
- On average, 1.9 VOCs were experienced by patients in the past year.

People living with sickle cell disease often don't seek care despite symptoms and complications.

- Of more than 11,000 VOCs reported by survey respondents, resulted in hospitalization while nearly one-quarter were managed at home.

When asked why they did not seek medical assistance for VOCs:

- 39% said the main reason they chose to manage their VOCs at home was due to a previous poor experience at the ER or hospital.
- 26% said they didn't seek assistance due to a perception that health care providers do not understand SCD.
- 19% said their VOCs are treated at home because the pain can be too severe to leave home.

Burden Beyond Physical

Sickle cell disease has a substantial impact on patients' emotional well-being and daily life.

- 41% of patients surveyed reported feeling anxious.
- 44% of patients surveyed reported feeling depressed.
- 45% stated a high impact on their family or social life.

Economic Impact

Sickle cell disease impacts patients’ ability to work and/or complete their education.

- 51% of respondents believe their income would be higher if they didn’t have the disease.
- 34% of respondents have changed from full-time to part-time employees because of SCD.
- 43% of respondents have considered leaving their job all together.

Surveyed patients, on average, reported over 1 day of missed work every week (8.3 hours over 7 days) because of their disease.

References: