

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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Disclosures

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- Consultant: Novartis, Global Blood Therapeutics, Novo Nordisk

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- Consultant, research support: Global Blood Therapeutics

Fernando F. Costa

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Zakareya Al Kadhem

- Nothing to disclose

Biba Tinga

- Nothing to disclose

Dianaba Ba

- Nothing to disclose

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Background and Objective



SCD has a substantial emotional and physical burden on patients and their caregivers.^{1,2}



Research on the impacts of SCD on patient and caregiver quality of life is limited, including research on the health inequalities faced by different groups around the world.¹



The limitations in research underscore the need **for greater understanding of the challenges of living with SCD in different communities.**



Objective: to broaden the understanding of the global impact of SCD on patients and their caregivers

SCD, sickle cell disease.

1. Osunkwo I, et al. *Am J Hematol.* 2021;96(4):404-417. 2. Madani BM, et al. *Health Qual Life Outcomes.* 2018;16(1):176.

SHAPE Survey Overview

Online, quantitative surveys to investigate:



- The experiences and unmet needs of **people living with SCD**
- The unmet needs of **those caring for and treating** people living with SCD



Samples of patients, caregivers, and HCPs included:



1. **Patients:** diagnosed with SCD by an HCP and aged ≥ 12 years













2. **Caregivers:** caring for someone diagnosed with SCD and aged ≥ 18 years



3. **HCPs**

Patient and Caregiver Population by Country

A total of 919 patients and 207 caregivers completed the survey.

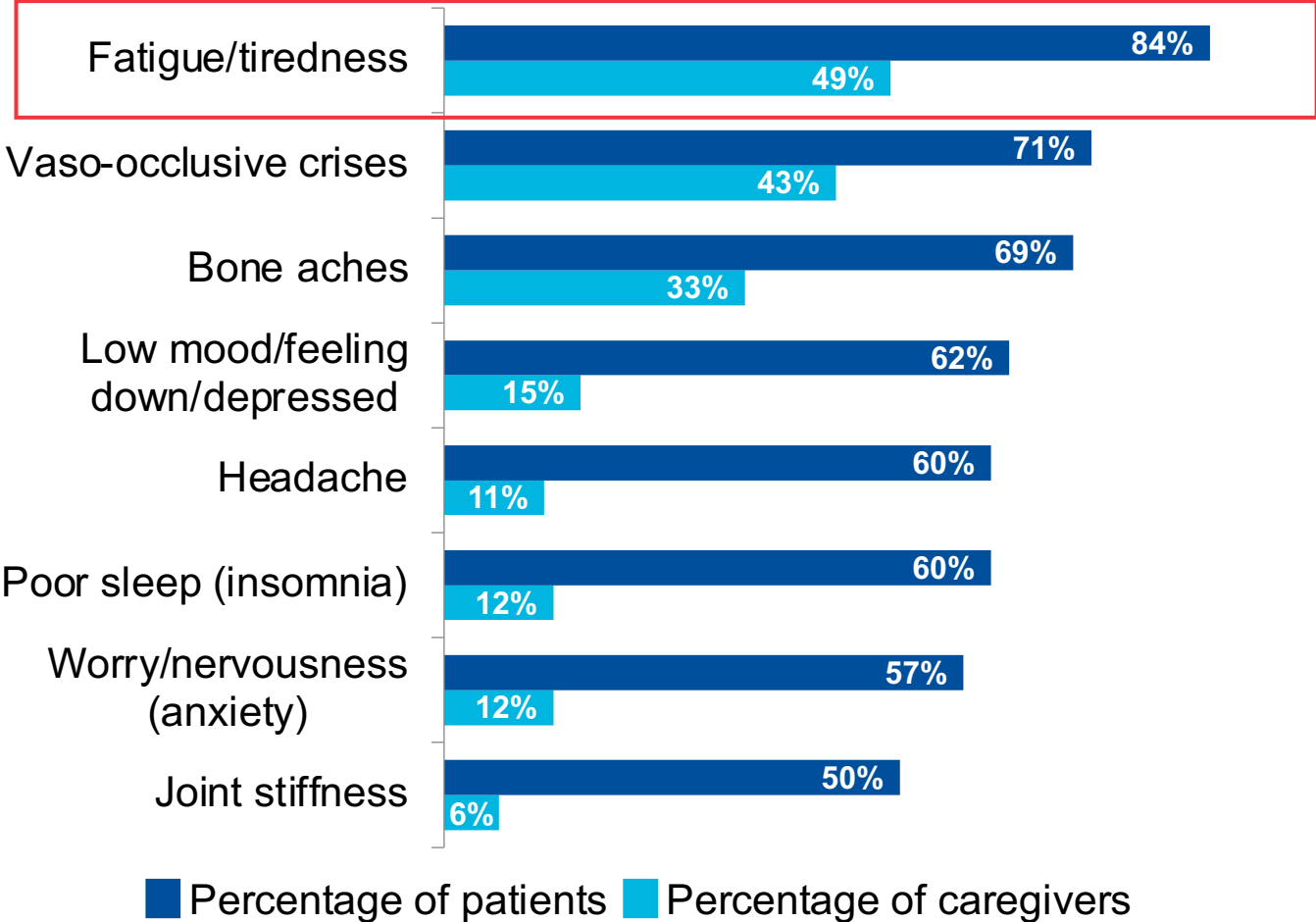
| | USA  | UK  | Brazil  | France  | Saudi Arabia  | United Arab Emirates  | Canada  | Bahrain  | Germany  | Oman  | TOTAL |
|------------|--|---|---|--|---|---|---|--|--|---|-------|
| Patients | 295 (32%) | 151 (16%) | 151 (16%) | 122 (13%) | 70 (8%) | 46 (5%) | 32 (3%) | 19 (2%) | 18 (2%) | 15 (2%) | 919 |
| Caregivers | 30 (14%) | 30 (14%) | 50 (24%) | 29 (14%) | 25 (12%) | 17 (8%) | 10 (5%) | 8 (4%) | 8 (4%) | 0 | 207 |

Sociodemographic Information for Patients and Caregivers

| Characteristic | Patients (n=919) | Caregivers (n=207) |
|---|-------------------------|---------------------------|
| Age, mean, years | 32.3 | 39.1 |
| 12 to <18, n (%) | 64 (7) | 0 |
| 18 to 39, n (%) | 648 (71) | 111 (54) |
| ≥40, n (%) | 207 (23) | 96 (46) |
| Gender identity, n (%) | | |
| Male | 257 (28) | 55 (27) |
| Female | 659 (72) | 149 (72) |
| Other/prefer not to say | 3 (<1) | 3 (1) |
| Current employment/educational status, n (%) | | |
| Working | 465 (51) | 143 (69) |
| Full-time | 257 (28) | 83 (40) |
| Part-time or self-employed | 208 (23) | 60 (29) |
| Student | 170 (18) | 7 (3) |
| Retired | 34 (4) | 7 (3) |
| Unemployed/not working | 274 (30) | 54 (26) |
| Don't know/prefer not to say | 11 (1) | 0 |

Patient Symptoms and Impacts on Patients and Caregivers

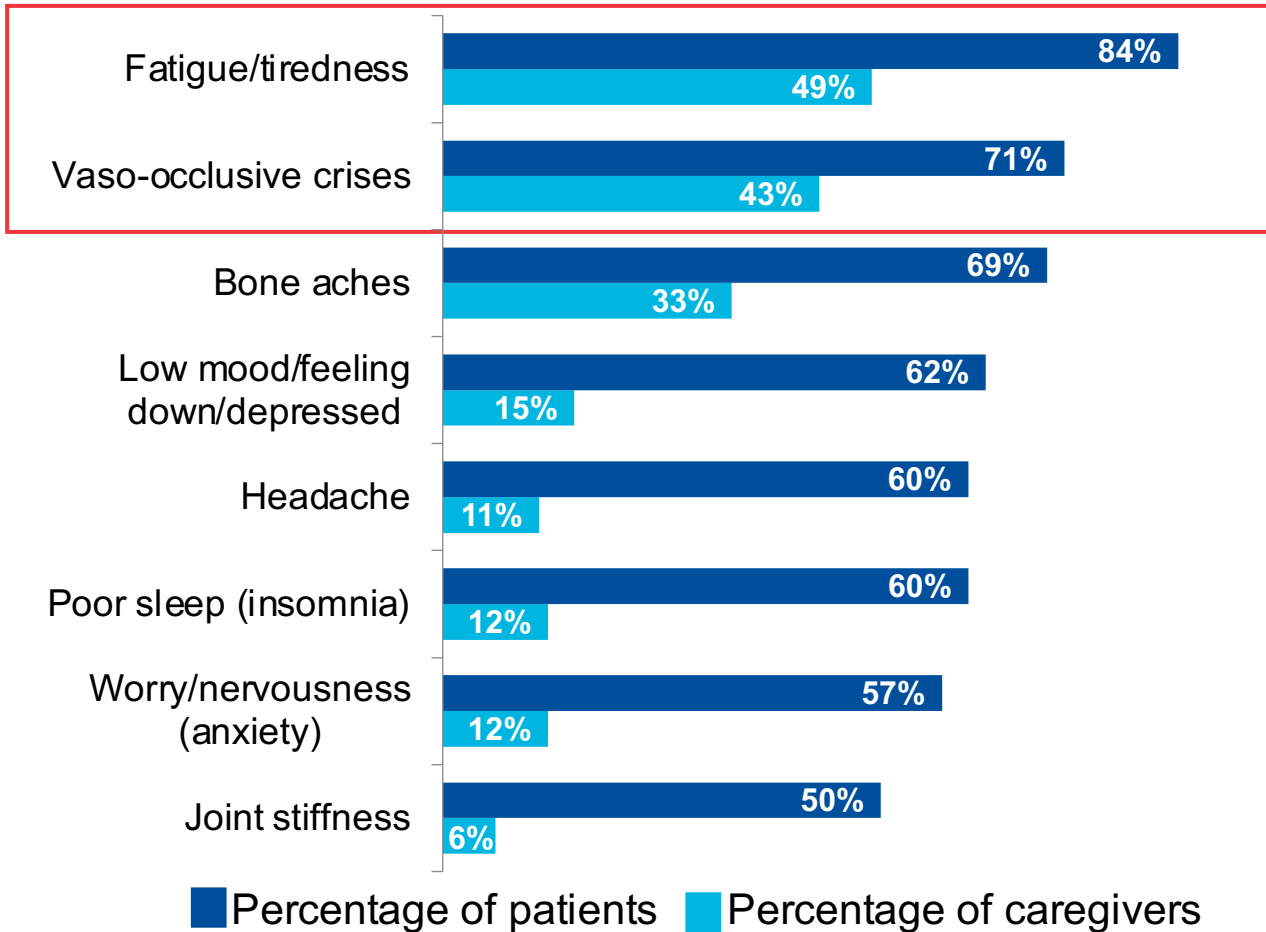
Top Symptoms Experienced by Patients in the Past Year (Occurring in $\geq 50\%$ of Patients) and Reported by Caregivers as Having the Greatest Impact on Their Lives



- **Fatigue** was the symptom experienced by the most patients in the past year and was reported as having the greatest impact on caregivers' lives.

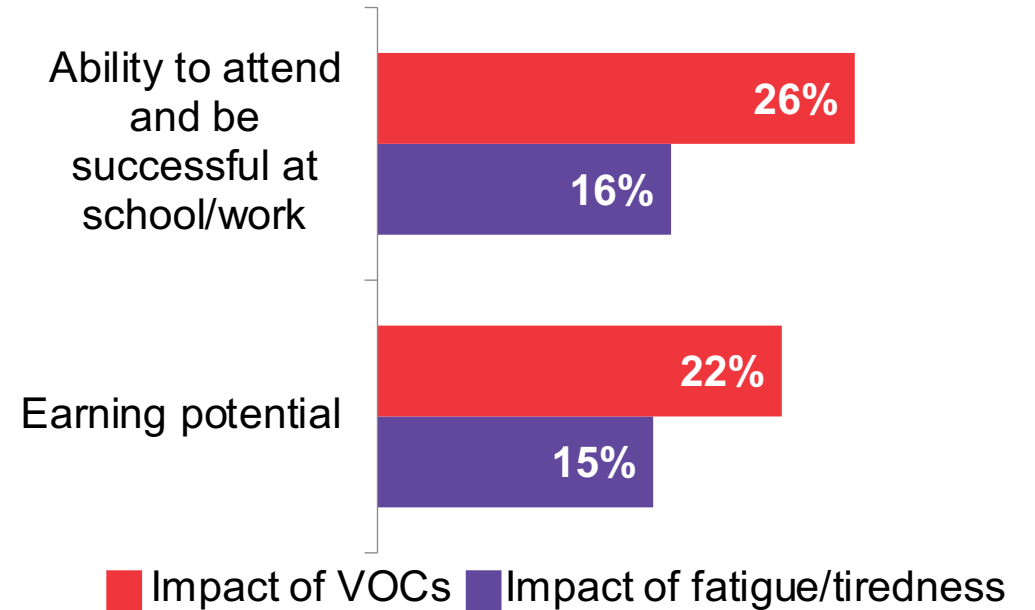
Patient Symptoms and Impacts on Patients and Caregivers *(continued)*

Top Symptoms Experienced by Patients in the Past Year (Occurring in $\geq 50\%$ of Patients) and Reported by Caregivers as Having the Greatest Impact on Their Lives



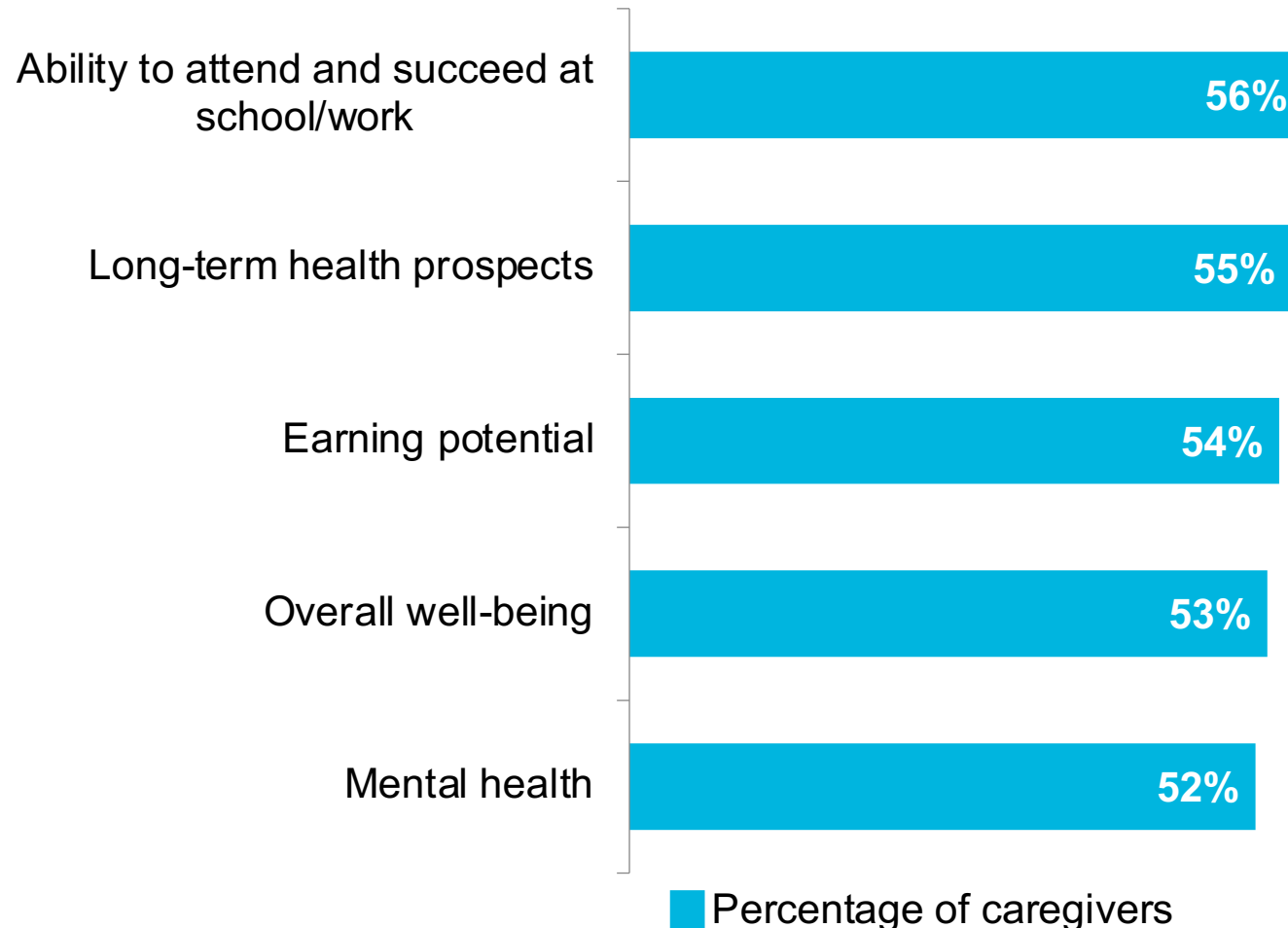
- **Fatigue/tiredness and VOCs** had the greatest impact on patients' ability to attend and be successful at school/work and on their earning potential.

Impact of Symptoms on Patient QOL



Patient Symptom Impacts on Caregivers' Lives

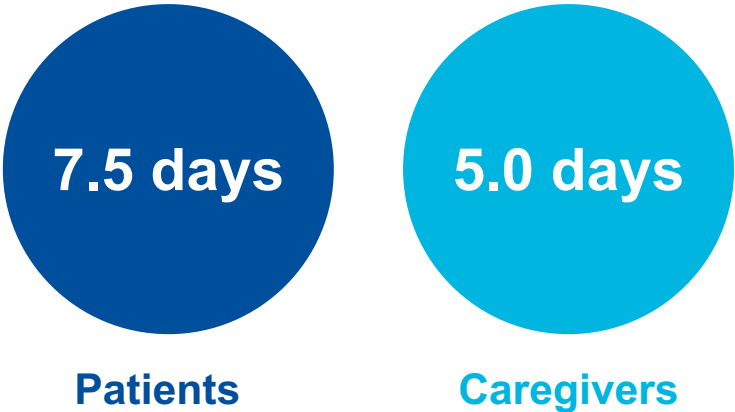
Most Impacted Areas of Caregivers' Lives



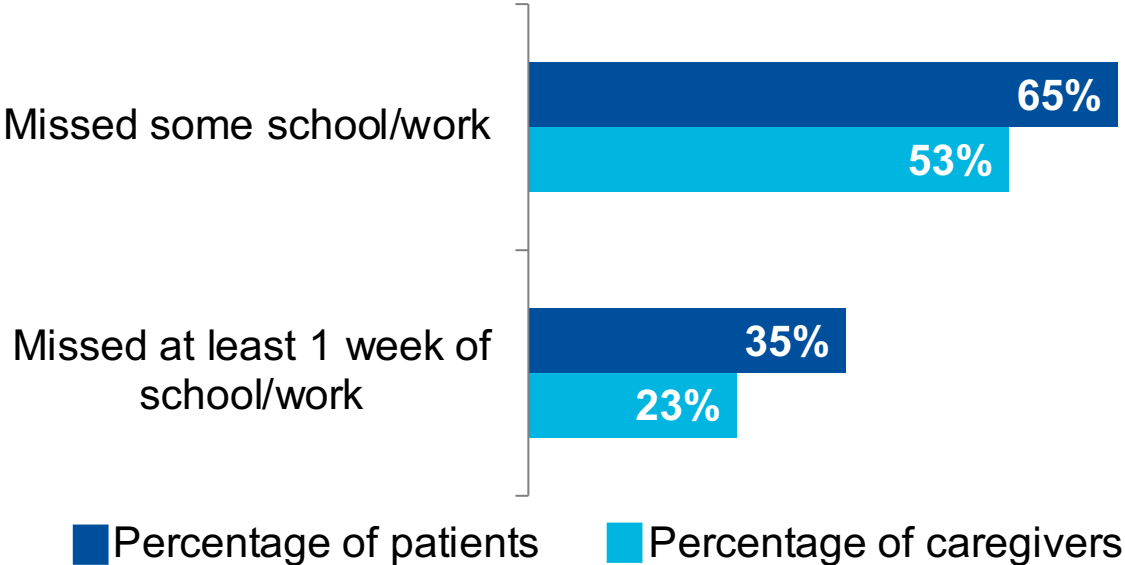
- Over half of caregivers reported that patient symptoms impacted various aspects of their lives, such as their **career and education, health, and overall well-being.**

Missed Days of School/Work

Average Days of School/Work Missed in the Past Month

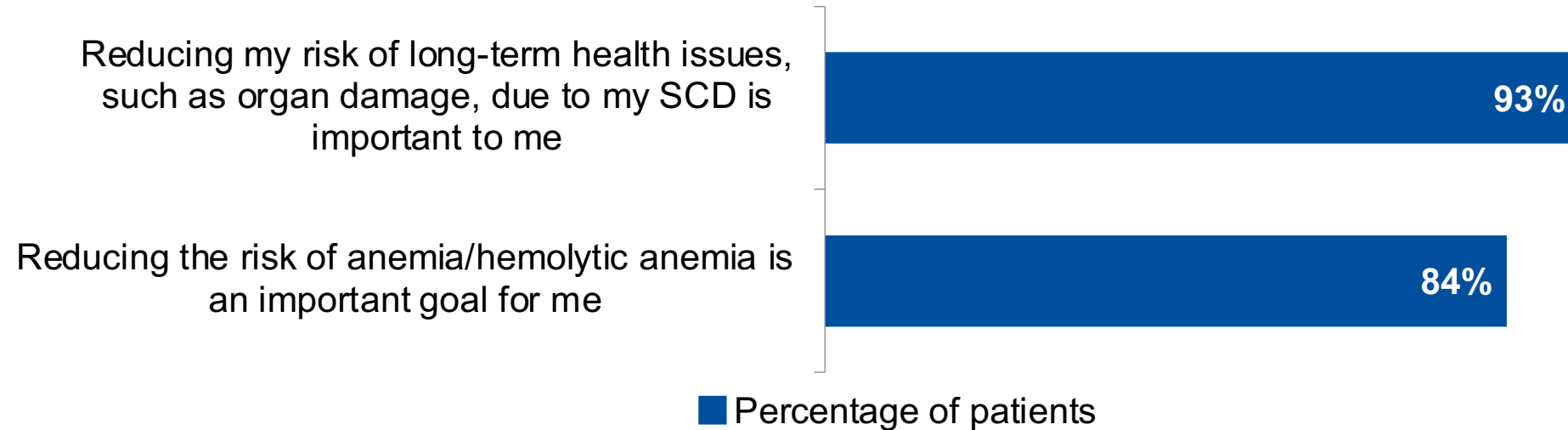


Patients and Caregivers Who Missed School/Work in the Past Month



Patient Perceptions of SCD Treatments

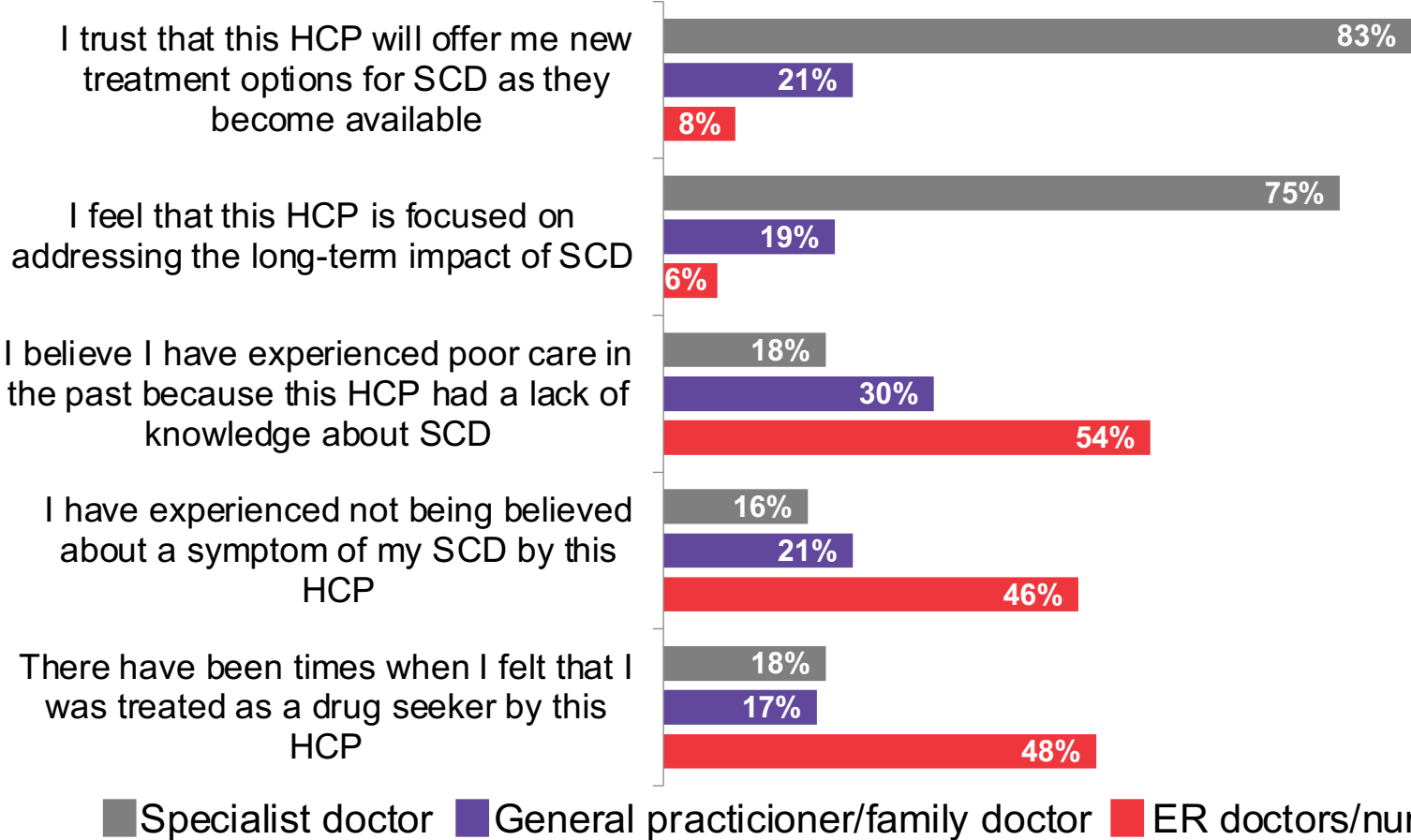
Patients Who Agreed^a With the Following Statements Regarding SCD Treatments



^aPercentages reflect patients who answered “somewhat agree” or “strongly agree” to this statement.
SCD, sickle cell disease.

Patient Relationship With HCPs

Patients Who Agreed^a With the Following Statements Regarding HCPs by Specialty



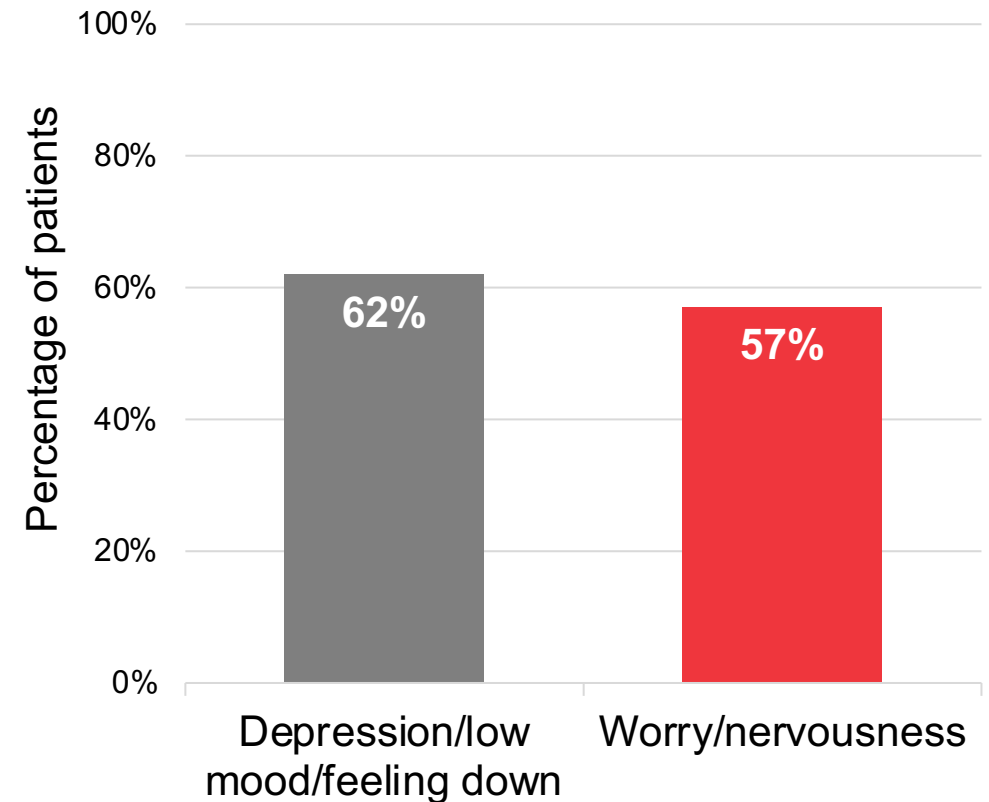
- Patients reported more positive experiences with their **specialist doctors** compared with ER HCPs.

^aPercentages reflect patients who selected the HCPs that this statement applied to regarding their experiences.
 ER, emergency room; HCP, healthcare professional; SCD, sickle cell disease.

Disease Impact on Patients' Mental Health

- In addition to physical symptoms, SCD impacts **QOL** through patients' emotional well-being and self-esteem.
- **Mental health symptoms** affected the majority of patients with SCD in the past year: 62% with depression/low mood/feeling down and 57% with worry/nervousness.
- **Depression/low mood/feeling down affected patients':**
 - Mental health (24%)
 - Self-esteem (18%)
 - Relationships/potential relationships (14%)
 - Family (13%)
 - Optimism about their future (12%)

Patients Who Experienced Poor Mental Health Symptoms in the Past Year



Conclusions

- These findings provide insight on the broad impacts of SCD and highlight areas that need more support or improvement:
 - Tools that address fatigue/tiredness and therapies that reduce the frequency of VOCs
 - Better recognition of the impact of SCD on caregivers' careers and well-being
 - Support for patients who feel they have received poor treatment
 - Resources to improve patients' mental health
 - Resources to increase ER HCPs' knowledge and understanding of SCD and patients with SCD

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