Sickle Cell Health Awareness, Perspectives, and Experiences Survey: US Patients/Caregivers

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Disclosures

Alan Anderson, MD

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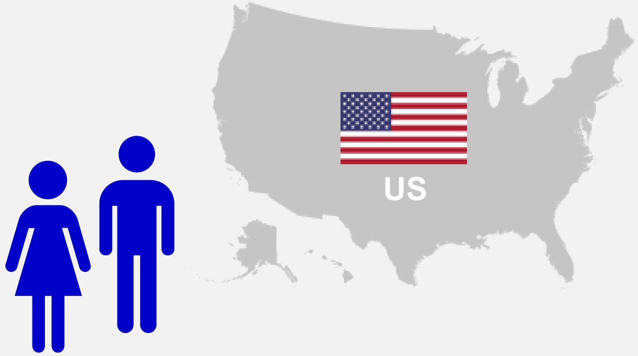
Overview

SCD

Lifelong complications

Patient and caregivers
Physical/emotional wellbeing[1]

Limited research on impact on QoL[2,3]



100,000 people living with SCD[4]

SCD occurs in:

- **1 in ~365** Black/African American births[4]
- **1 in ~16,300** Hispanic American births[4]

Need to identify and address **challenges faced** by **people with SCD**

SHAPE Survey

To **improve understanding** of global **impact of SCD on patients** and their **caregivers**

Presentation aim

To report findings from the **SHAPE survey in the US** within context of insights obtained **globally**

QoL=quality of life; SCD=sickle cell disease; SHAPE=Sickle Cell Health Awareness, Perspectives and Experiences

1. Madani BM, et al. Health Qual Life Outcomes 2018;16(1):176. **2.** Osunkwo I, et al. Am J Hematol 2021;96(4):404-17. **3.** McClish DK, et al. Health Qual Life Outcomes 2005;3:50. **4.** Centers for Disease Control and Prevention. Data & Statistics on Sickle Cell Disease. Accessed June 2, 2023. https://www.cdc.gov/ncbddd/sicklecell/data.html.

SHAPE Survey Overview

Online, quantitative surveys of closed-ended questions to investigate:

- Circumstances and experiences of respondents
- Unmet needs of **people living with SCD** and of **those caring for** and **treating** people living with SCD

PARTICIPANTS	CRITERIA
Patients	• Aged ≥12 years • Diagnosed with SCD by an HCP
Caregivers	• Aged ≥18 years • Caring for someone diagnosed with SCD
HCPs	• In clinical practice for 3 to 35 years • ≥10 patients with SCD under their care

HCP=healthcare professional; SCD=sickle cell disease; SHAPE=Sickle Cell Health Awareness, Perspectives and Experiences

Patient and Caregiver Population by Country

Of 919 patients and 207 caregivers interviewed globally,
295 patients and **30 caregivers** were from **the US**

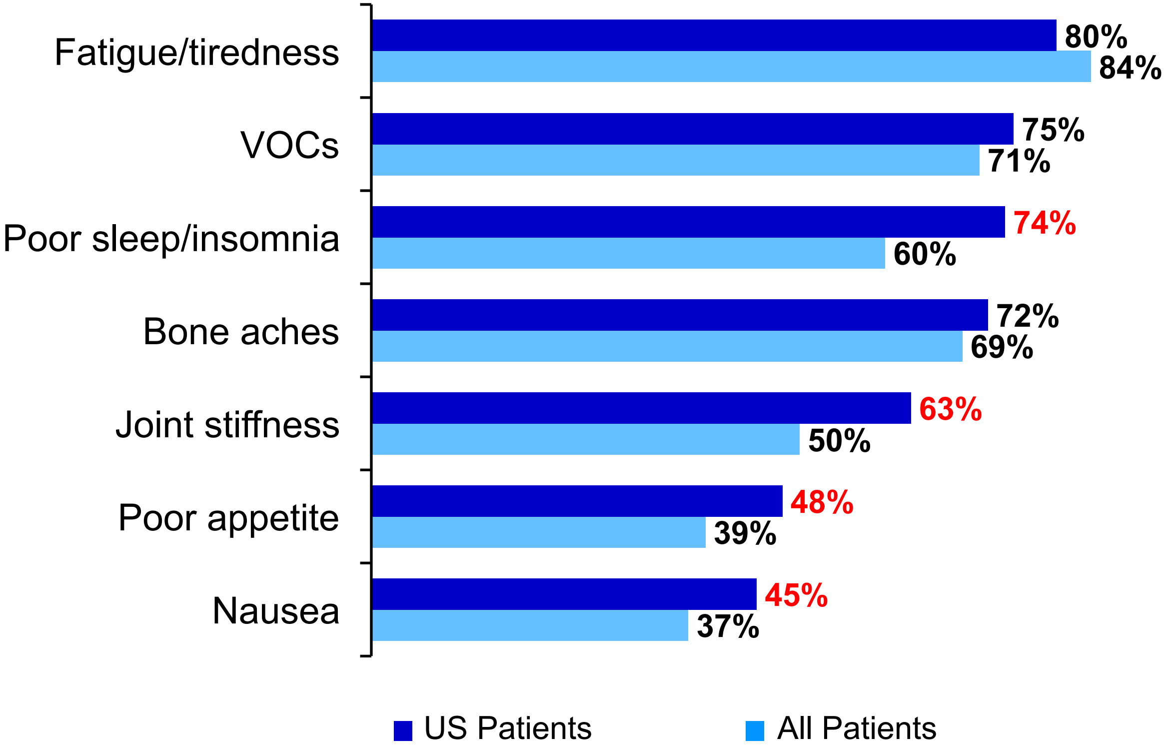
	US	UK	Brazil	France	Saudi Arabia	UAE	Canada	Bahrain	Germany	Oman	TOTAL
Patients	295 (32%)	151 (16%)	151 (16%)	122 (13%)	70 (8%)	46 (5%)	32 (3%)	19 (2%)	18 (2%)	15 (2%)	**919**
Caregivers	30 (14%)	30 (14%)	50 (24%)	29 (14%)	25 (12%)	17 (8%)	10 (5%)	8 (4%)	8 (4%)	0	**207**

UAE=United Arab Emirates

Sociodemographic Information for Patients and Caregivers

	Patients		Caregivers	
Characteristic	**US (n=295)**	**Total (N=919)**	**US (n=30)**	**Total (N=207)**
Age, mean, years	33.6	32.3	39.2	39.1
12 to <18, n (%)	14 (5)	64 (7)	0	0
18 to 39, n (%)	213 (72)	648 (71)	15 (50)	111 (54)
≥40, n (%)	68 (23)	207 (23)	15 (50)	96 (46)
Female, n (%)	218 (74)	659 (72)	25 (83)	149 (72)
Current employment/educational status, n (%)				
Working full-time	77 (26)	257 (28)	18 (60)	83 (40)
Working part-time or self-employed	78 (26)	208 (23)	7 (23)	60 (29)
Student	49 (17)	170 (18)	1 (3)	7 (3)
Retired	13 (4)	34 (4)	2 (7)	7 (3)
Unemployed/not working	91 (31)	274 (30)	3 (10)	54 (26)
Highest educational achievement, n (%)				
Primary school	44 (15)	100 (11)	0	8 (4)
Secondary school	44 (15)	222 (24)	5 (17)	61 (29)
Technical college/apprenticeship	63 (21)	168 (18)	6 (20)	40 (19)
University degree	102 (35)	299 (33)	15 (50)	62 (30)
Masters/PhD	32 (11)	110 (12)	4 (13)	29 (14)

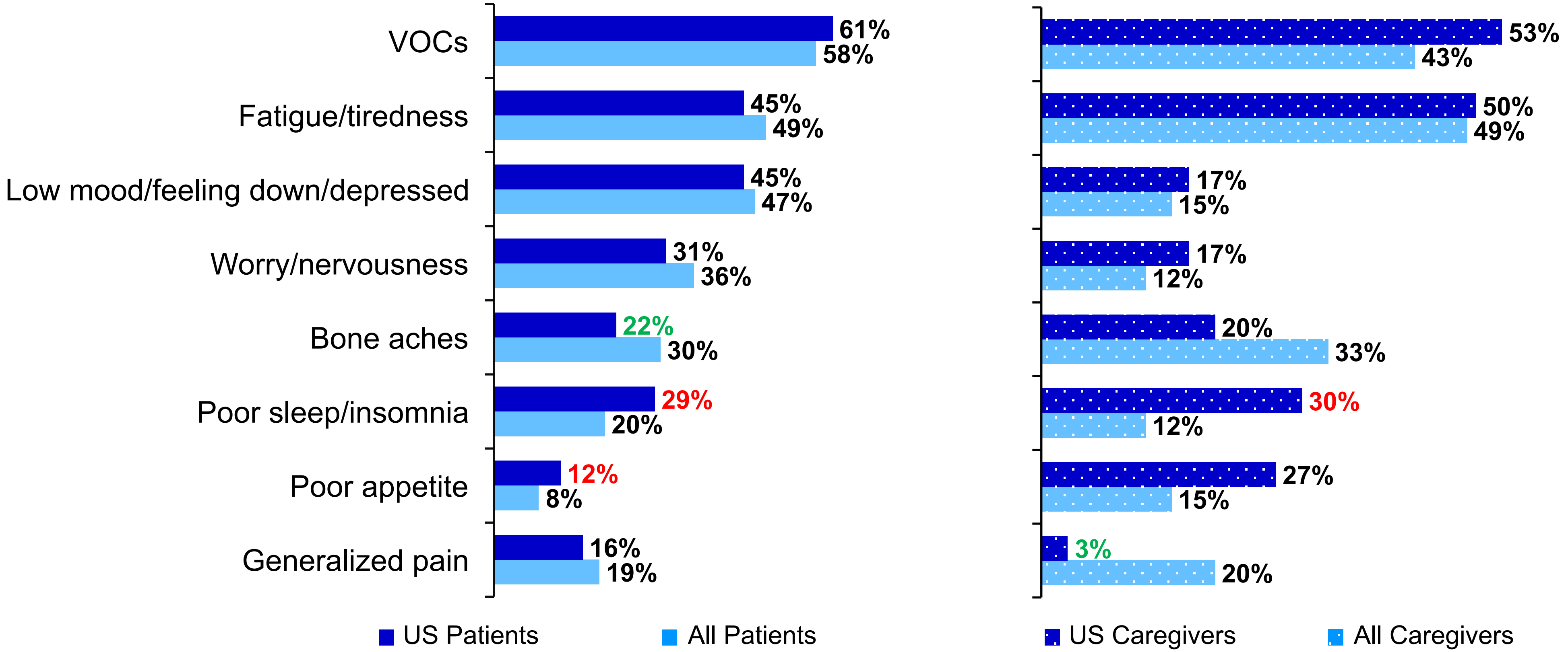
Symptoms Experienced by Patients in the Past Year



- **Fatigue/tiredness** and **VOCs** were the **symptoms experienced most frequently** by all patients and US patients.
- Compared with all patients, **higher percentages of US patients** experienced **poor sleep/insomnia**, **joint stiffness**, **poor appetite**, and **nausea**.

Red indicates a significantly higher percentage of US patients vs all patient respondents. Statistical testing was based on a t-test with an α level of 0.05.
Responses to the question "In the past year, which of the following signs and symptoms, if any, have you experienced?" Symptoms occurring in ≥70% of US patients or those with significant differences in US patients vs all patient respondents are presented.
VOC=vaso-occlusive crisis

Patient Symptoms That Had the Greatest Impact on Lives of Patients and Caregivers[a]



Red indicates a significantly higher percentage of US respondents vs all respondents. **Green** indicates a significantly lower percentage of US patients vs all patient respondents.

[a] Occurring in ≥30% of all patients or with significant differences in US respondents vs all respondents.

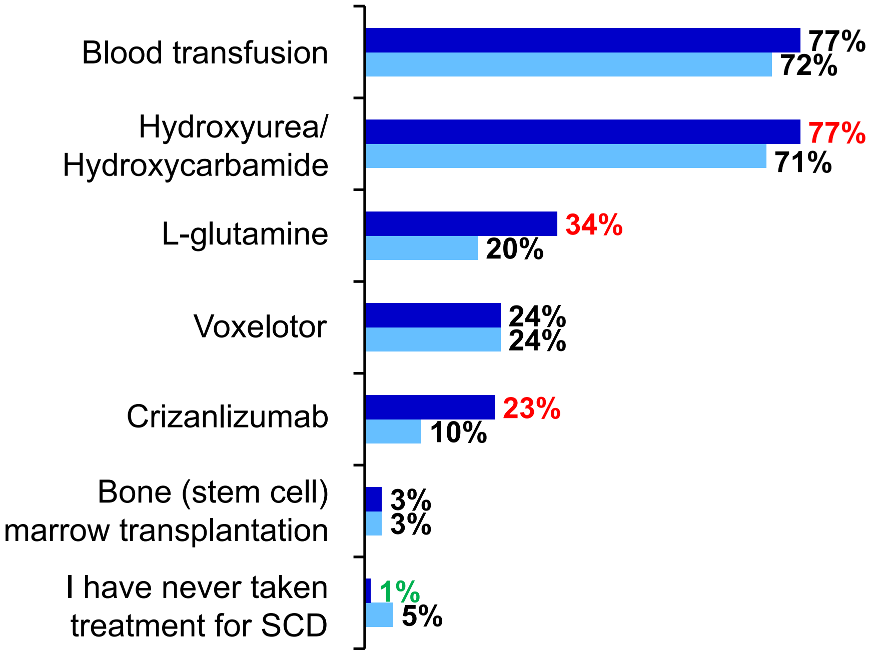
Left panel: Patients' responses to the question "Of the symptoms you have indicated in the previous question that you have experienced, which has had the biggest impact, on the following areas of your life?"

Right panel: Caregivers' responses to the question "Which of the following signs or symptoms, if any, which may be experienced by the person you care for has the biggest impact on your life?

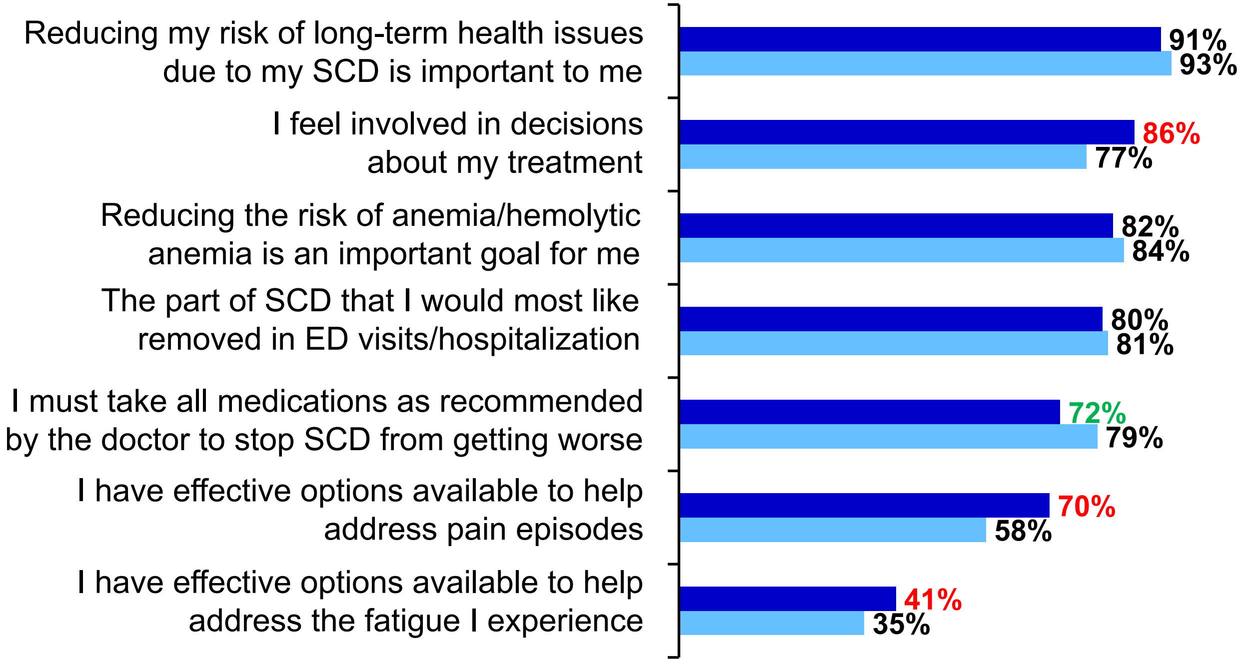
VOC=vaso-occlusive crisis

Patients’ Perceptions and Experience of SCD Treatments

SCD Treatments Patients Have Taken/Experienced[a]



Patients Who Agreed With the Following Statements Regarding SCD Treatments[b]



■ US Patients ■ All Patients

Red indicates a significantly higher percentage of US patients vs all patient respondents. **Green** indicates a significantly lower percentage of US patients in vs all patient respondents.

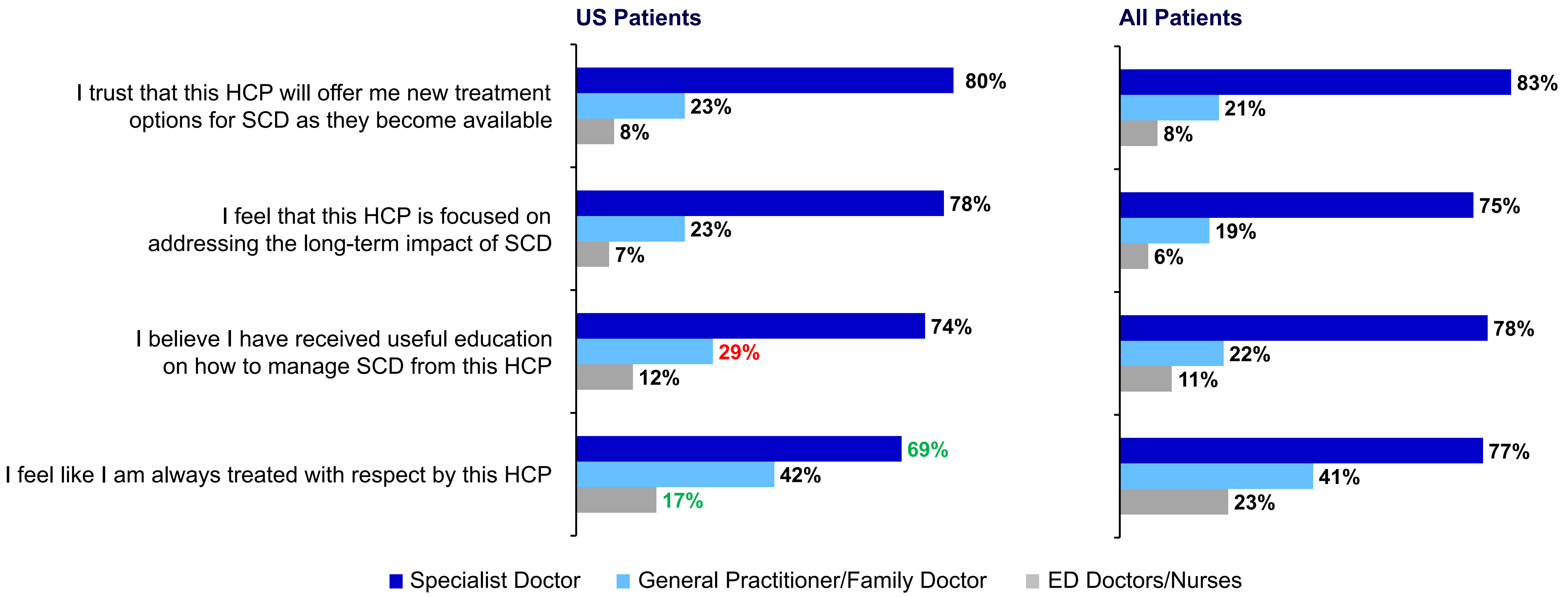
[a] Responses to the question “Which of the follow treatments for SCD, if any, have you taken/experienced?”

[b] Percentages reflect patients who answered “somewhat agree” or “strongly agree” with the statement; in ≥80% of all patients or with significant differences in US patients vs all patient respondents.

ED=emergency department; SCD=sickle cell disease

Patient Perception of Care Received From Different HCPs (1)

Patients Who Agreed With the Following Statements[a]



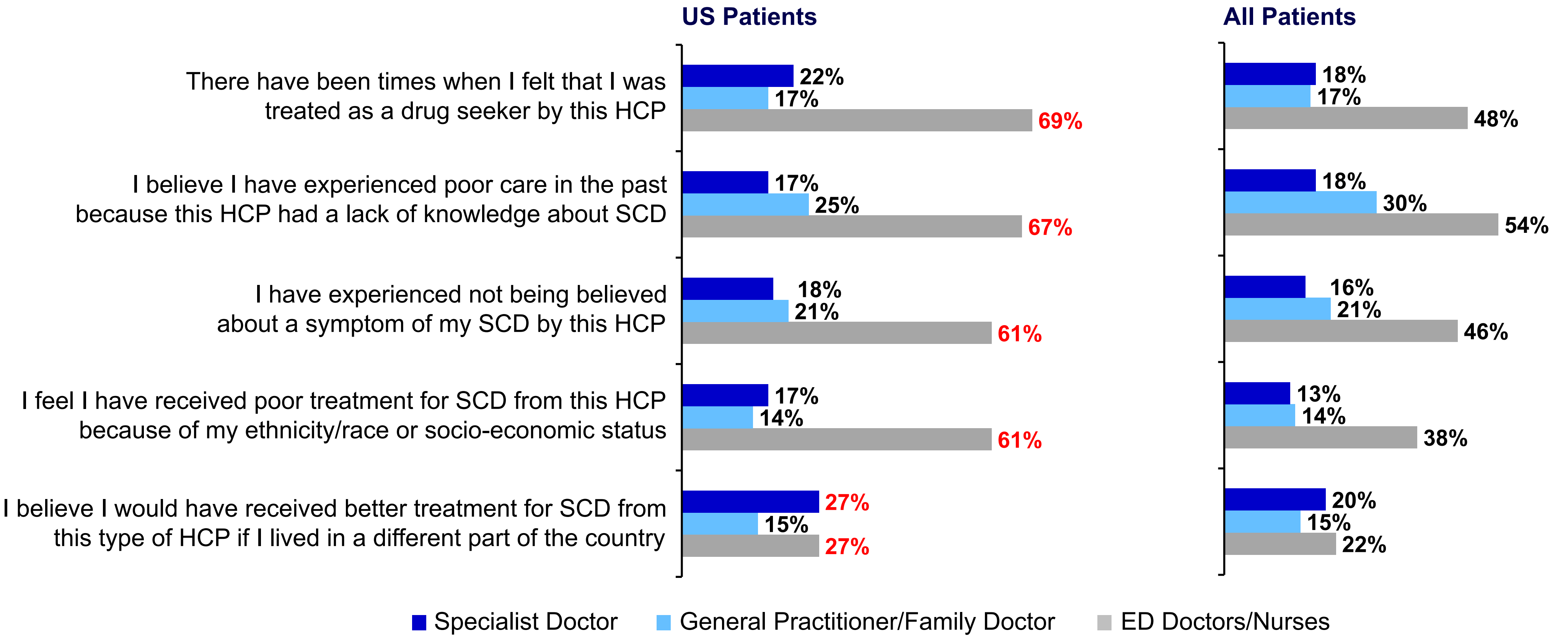
Red indicates a significantly higher percentage of US patients vs all patient respondents. **Green** indicates a significantly lower percentage of US patients vs all patient respondents.

[a] Percentages reflect patients who selected the types of HCPs that this statement applied to regarding their experiences.

ED=emergency department; HCP=healthcare professional; SCD=sickle cell disease

Patient Perception of Care Received From Different HCPs (2)

Patients Who Agreed With the Following Statements[a]

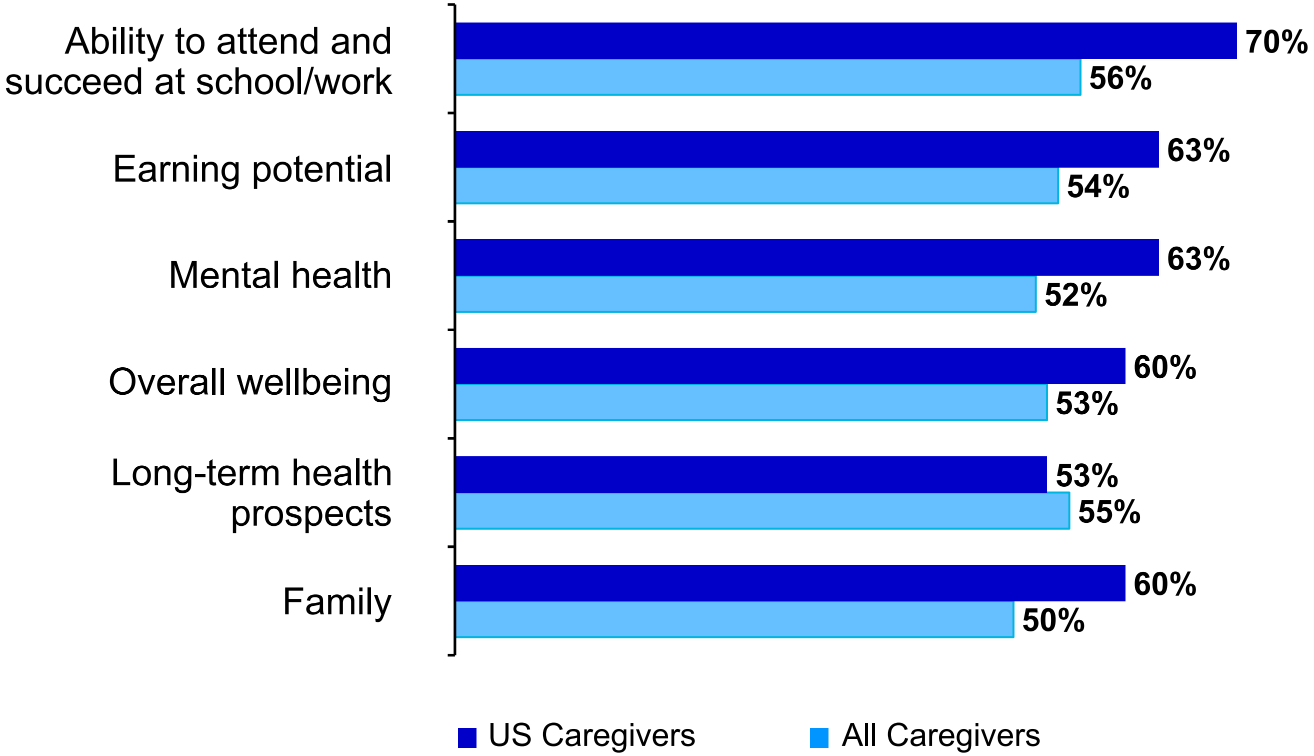


Red indicates a significantly higher percentage of US patients vs all patient respondents. **Green** indicates a significantly lower percentage of US patients vs all patient respondents.

[a] Percentages reflect patients who selected the types of HCPs that this statement applied to regarding their experiences.

ED=emergency department; HCP=healthcare professional; SCD=sickle cell disease

Areas in the Lives of Caregivers That Were Most Impacted by Caring for Patients

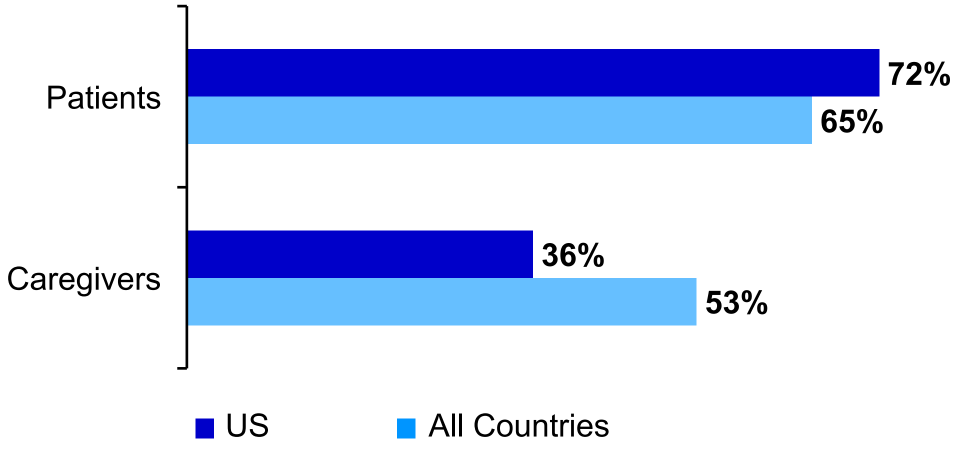


- More than half of all caregivers reported that **caring for someone with SCD affects** various aspects of their lives.
- The **top 3 areas of impact** identified by US caregivers were **ability to attend and succeed at school/work**, **earning potential**, and **mental health**.

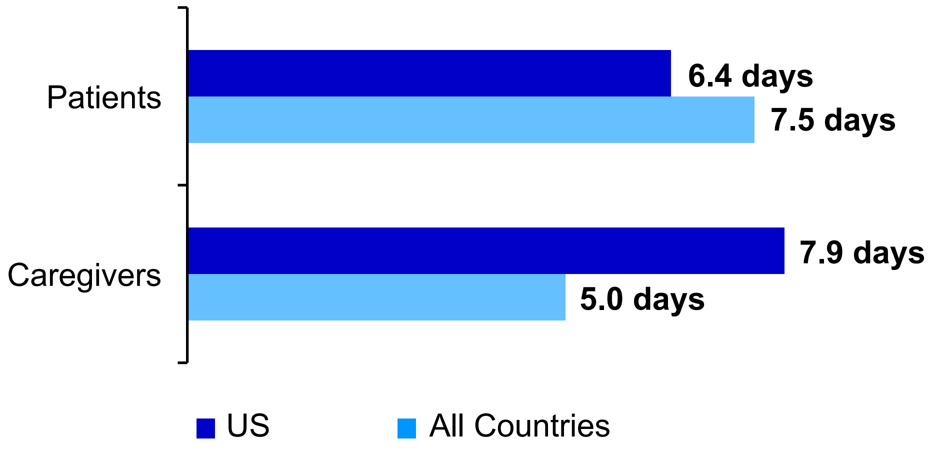
Responses to the question “To what extent, if at all, does caring for someone living with SCD impact the following areas of your life?”
SCD=sickle cell disease

Impact of SCD on School and Work for Patients and Caregivers

Patients and Caregivers Who Missed ≥1 Day of School/Work in the Past Month: **US** and **All Countries**



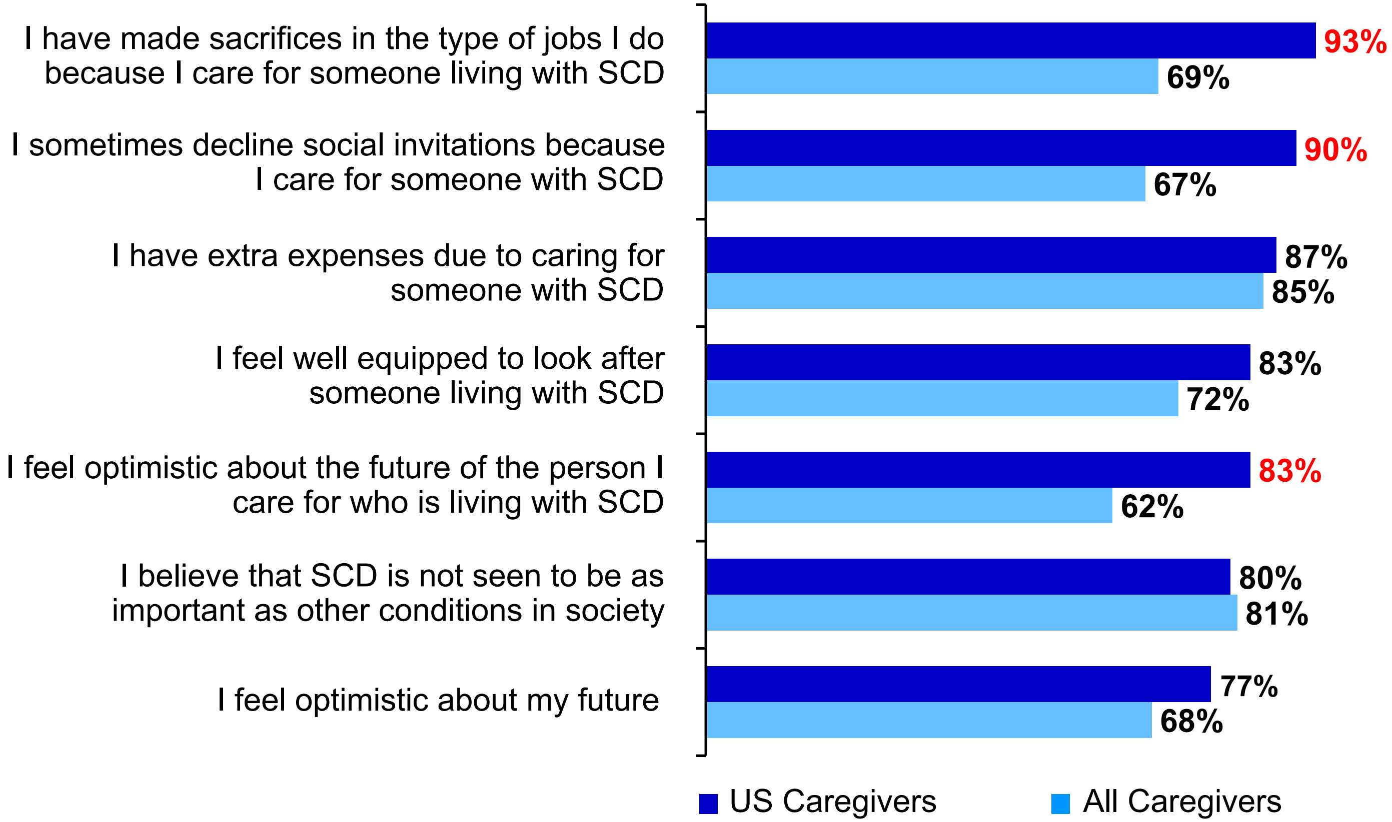
Average Days of School/Work Missed by Patients and Caregivers in the Past Month: **US** and **All Countries**



Responses to the question “How many hours or days, if any, did you miss from work or school/college because of health problems linked to sickle cell disease?”
SCD=sickle cell disease

Caregivers’ Feelings and Experiences of Caring for Patients

Caregivers Who Agreed With the Following Statements Regarding Caring for Patients[a]



- Compared with all caregivers, more **US caregivers** agreed that they **made sacrifices in their types of jobs** and **declined social invitations**.
- A higher percentages of US caregivers agreed that they **felt optimistic about the future of the person they care for with SCD** compared with all caregivers.

Red indicates a significantly higher percentage of US caregivers vs all caregiver respondents.

[a] Percentages reflect caregivers who answered “somewhat agree” or “strongly agree” with the statement.

SCD=sickle cell disease

Conclusions

Findings reported in this survey emphasize the need for **targeted symptom management** to improve the **QoL of affected individuals in the US**.

Compared with all patient respondents, a **significantly higher percentage of patients with SCD in the US** experienced symptoms of **poor sleep**, **joint stiffness**, **poor appetite**, and **nausea** within the last year.

Compared with all caregivers, a **lower percentage of US caregivers missed ≥1 day per month of school/work** (36% vs 53%), but the average **number of days missed was higher** (7.9 vs 5.0 days).

A higher percentage of US caregivers agreed that they were **optimistic about the future of the person they care for with SCD** compared with all caregivers.

Overall, responses to the **SHAPE survey** described herein highlight the **need for resources to support patients with SCD and their caregivers in the US**.

QoL=quality of life; SCD=sickle cell disease; SHAPE=Sickle Cell Health Awareness, Perspectives and Experiences

Acknowledgments

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Disclosures

AA: consultant fees from Novo Nordisk, Pfizer, Vertex; research funding from Pfizer. **RH:** CEO and President of Sickle Cell Disease Association of America, Inc. **JJ:** CEO of Sickle Cell Society. **BT:** President of Sickle Cell Disease Association of Canada. **EI:** President of IST e.V. **MdM:** consultant fees from Addmedica, Novartis, Vertex. **FFC:** consultant fees from Novartis. **WJ:** consultant fees and honoraria from Amgen, Bayer, Novartis. **JBK:** consultant fees from bluebird bio, Novartis, Pfizer. **IO:** consultant fees from Novartis, Novo Nordisk; honorarium from Pfizer. **BL:** former employee of Ipsos Healthcare. **BPDI:** educational funding from AstraZeneca, bluebird bio, Celgene, Novartis, Pfizer; honararia from Agios, Cyclerion, Forma Therapeutics, Nova, Novartis, Novo Nordisk, Pfizer.

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