Sickle Cell Disease

Knowledge and Practices Among Healthcare Providers: Results of a National Survey

Prepared by the *Blood Diseases & Disorders Education Program* of the National Heart, Lung, and Blood Institute in collaboration with CVS Health®

National Heart, Lung, and Blood Institute

Blood Diseases & Disorders Education Program

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OVERVIEW

Background

Sickle cell disease (SCD) is the most common inherited blood disorder in the United States. In SCD, red blood cells are typically misshapen into a crescent or "sickle" shape, which can block the flow of blood through the body and cause recurring episodes of pain, called pain crises. Despite their extensive healthcare needs, many people living with SCD have difficulty getting appropriate care. As care partners of SCD specialists, primary care providers (PCP), pediatricians, and obstetrician-gynecologists (OB-GYN) play integral roles in helping people living with SCD manage their health. These healthcare providers' knowledge of preventive care, pain management, and awareness and use of current clinical practice guidelines impacts their ability to provide comprehensive and effective care for people living with SCD and to coordinate care with SCD specialists as appropriate.

The National Heart, Lung, and Blood Institute (NHLBI) of the National Institutes of Health (NIH) advances clinical care for people living with SCD by leading and supporting research and programs in the United States and around the world. NHLBI's *Blood Diseases & Disorders Education Program* (*BDDEP*) is a national health education program that aims to bring greater visibility to blood diseases and disorders, including SCD, as well as blood donation and safety by translating research for patients and professionals. CVS Health® has a longstanding commitment to helping ensure that people, including those living with SCD, have a fair and just opportunity to achieve optimal health.

BDDEP and CVS Health® collaborated on a national survey of healthcare providers to better understand their knowledge of SCD and to help inform the development of educational resources for providers and people living with SCD. The survey was designed to identify the current state of self-reported awareness and knowledge gaps specific to the care of patients with SCD to better understand what healthcare providers know, where they get information, and what assistance they need in providing care for people living with SCD.

Methodology

BDDEP and CVS Health® conducted an online survey with select healthcare providers between Aug. 28, 2023 and Sept. 13, 2023. For inclusion in the survey, healthcare providers completed a set of screener questions that assessed years of practice, plans to continue practicing for the next 5 years, number of patients they saw in an office setting in an average week, perceived knowledge of SCD, experience managing patients with SCD, and the number of patients with SCD they saw within the last 12 months. Additionally, the healthcare providers shared demographic information about their location and type of practice. Healthcare providers were invited to complete the full survey if they met the following criteria: had more than 2 years of experience, planned to continue practicing for at least 5 more years, saw more than 50 patients weekly, and cared for at least 2 patients with SCD within the last 12 months. The full survey asked about respondents' knowledge and awareness of SCD, knowledge of current treatment options, and comfort and experience providing care for people living with SCD. Findings from the survey provide a sample of experiences that may or may not be generalizable to other healthcare providers.

Results

Of the 884 respondents who completed the screener, 497 (56%) met the inclusion criteria and completed the full survey. Knowledge levels of SCD were highest among healthcare providers who reported seeing patients with SCD more often. Less than half (48%) of respondents reported being knowledgeable about current treatment options, including disease modifying therapies and gene therapies for SCD,[1] and 26% expressed they were very or somewhat familiar with gene therapies being developed for patients with SCD. Although most respondents (73%) agreed that opioids are appropriate for acute pain crises, less than half (42%) of the respondents reported prescribing opioids often for SCD pain management.

PCPs were more likely to work directly with patients with SCD to manage their condition, while OB-GYNs were most likely to refer patients to a specialist. Healthcare providers preferred to receive educational resources on SCD treatment guidelines and options through journal articles (65%) and continuing medical education (CME) programs (64%). More than 4 out of 5 (84%) respondents indicated they want information on new medication options and current and concise guidelines regarding care for patients with SCD.

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[1] At the time of this research, voxelotor was approved by the U.S. Food and Drug Administration (FDA) for the treatment of SCD. It was voluntarily withdrawn from the market by the manufacturer in September 2024.

RESEARCH OBJECTIVES

The primary objectives of the research were to:

1. Assess healthcare providers' knowledge of SCD and their knowledge of, perceptions of, and experience with managing the care of patients with SCD.
2. Understand how healthcare providers treat and support patients with SCD.
3. Identify opportunities for SCD education and address gaps in treatment needs.

Desired learnings included:

- How do healthcare providers care for patients with SCD?
- Does geography impact healthcare provider awareness and perceptions of SCD or how they care for patients with SCD?
- What do healthcare providers know about current SCD treatment options?
- What challenges do healthcare providers face in managing pain and other SCD health consequences for their patients?
- Where do healthcare providers seek additional education and health information on SCD?

METHODOLOGY

BDDEP and CVS Health® conducted an online survey with healthcare providers between Aug. 28, 2023 and Sept. 13, 2023.

Inclusion Criteria for Target Sample

Healthcare providers had to meet the following inclusion criteria to participate in the survey:

- Practiced in the United States.
- Identified as a PCP practicing family medicine, general medicine, or internal medicine; a pediatrician; or an OB-GYN
- Practiced medicine for at least 2 years and planned to continue practicing for at least the next 5 years
- Treated at least two patients with SCD annually
- Saw more than 50 patients per week

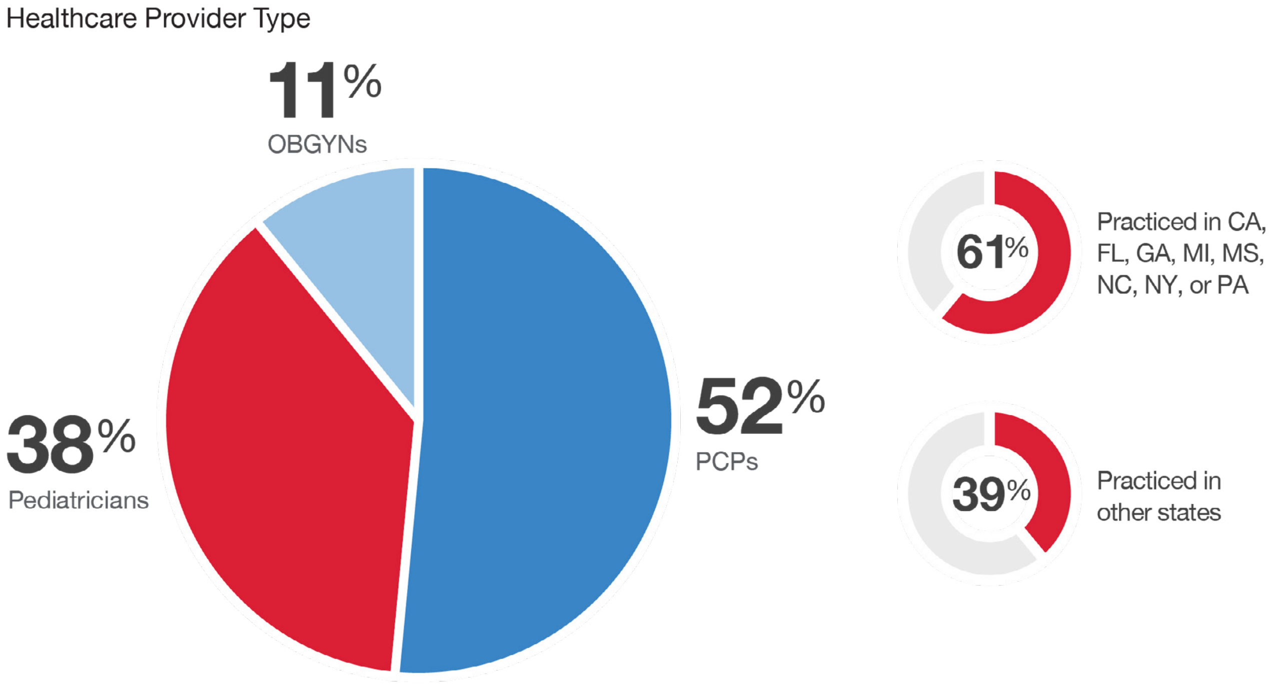
The survey consisted of screener profiling questions as well as substantive questions that used Likert scale, multiselect, and open-ended free-text question formats to assess healthcare providers' knowledge and awareness of SCD, understanding of current SCD treatment options, and comfort and experience with providing care for patients with SCD.

RESULTS

Demographics

Fifty-two percent of respondents were PCPs, with family medicine, general medicine, and internal medicine all represented. Pediatricians represented 38%, and 11% were OB-GYNs. Sixty-one percent of respondents practiced in California, Florida, Georgia, Michigan, Mississippi, New York, North Carolina, or Pennsylvania. See Figure 1.

Figure 1: Healthcare Provider Characteristics (*n* = 497)



Healthcare Provider Type

S2. Which of the following best describes your primary specialty? [Single select]

As shown in Table 1, regardless of healthcare provider type, respondents reported similar average numbers of patients per month. Specifically, OB-GYNs saw an average of 10 patients with SCD per month compared to 13 patients seen by PCPs and pediatricians.

Table 1: Overview of Patient Volume by Healthcare Provider Type (*n* = 497)

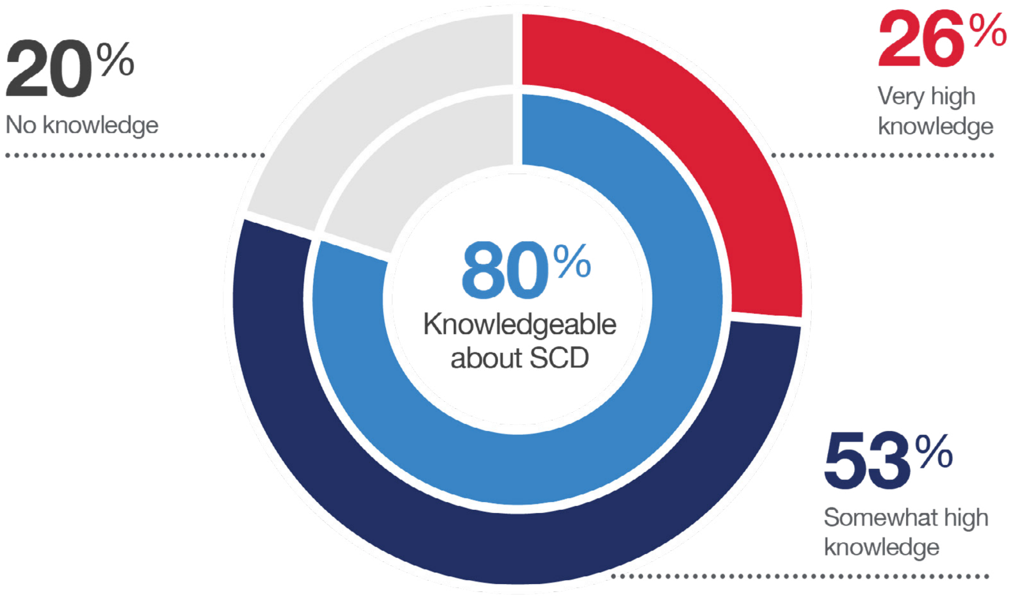
Healthcare Provider Type	Average Number of Patients/Week	Average Number of Patients with SCD/Month
Total Sample	123	12
PCPs	124	13
Pediatricians	120	13
OB-GYNs	124	10

S5. Approximately how many patients do you personally see in an average week in an office visit setting, not in a hospital or a research study? [Open-ended response]

Levels of SCD Knowledge

Although most healthcare providers (80%) reported being knowledgeable about SCD, more than half (53%) reported their knowledge of the disease is only somewhat high. Twenty-six percent of respondents indicated a very high knowledge of the disease. See Figure 2. Knowledge levels of SCD were highest among healthcare providers who reported seeing patients with SCD more often.

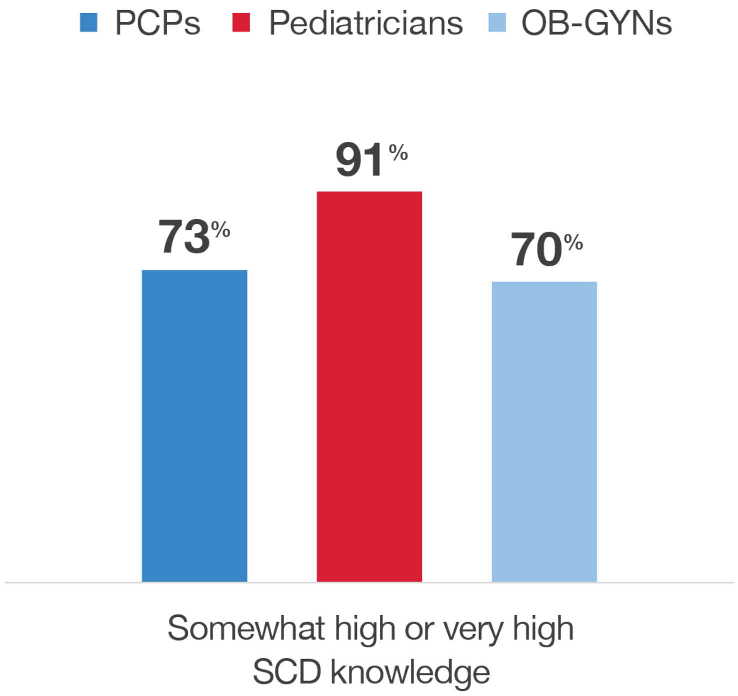
Figure 2: Healthcare Provider Knowledge of SCD (*n* = 497)



S6. How would you rate your level of knowledge about the following conditions? [Sickle Cell Disease, 1-4 Likert Scale]

Among respondents who cared for patients with SCD, 91% of pediatricians reported having "somewhat high" or "very high" SCD knowledge, as compared to 73% of PCPs and 70% of OB-GYNs. See Figure 3.

Figure 3: Knowledge of SCD by Healthcare Provider Type (*n* = 497)

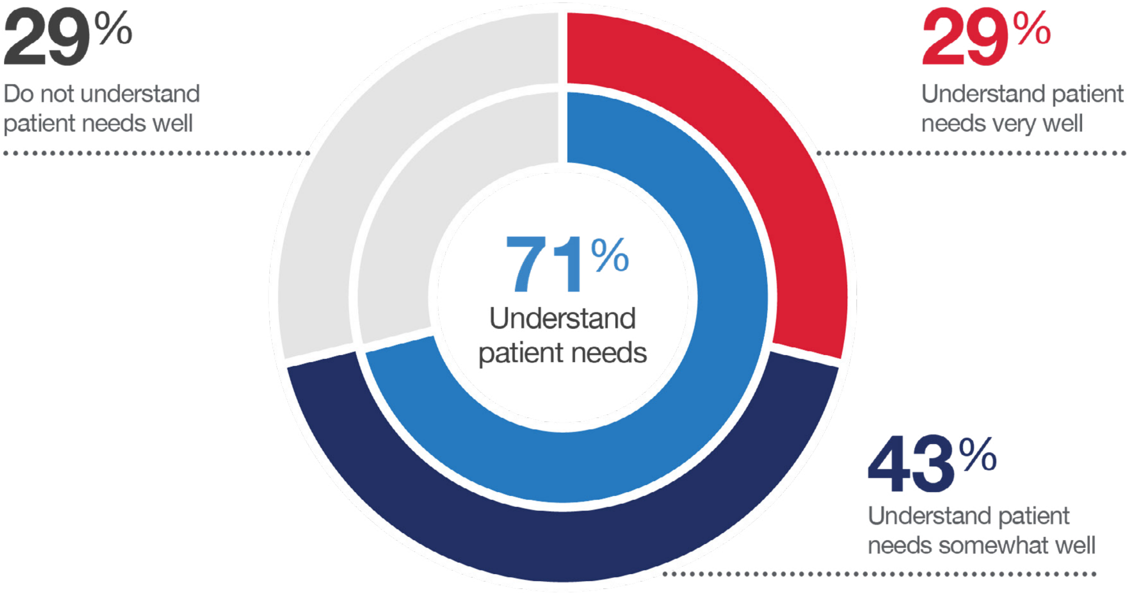


S6. How would you rate your level of knowledge about the following conditions? [Sickle Cell Disease, 1-4 Likert Scale]

Understanding SCD and the Needs of Patients with SCD

Most healthcare providers (71%) reported that they understood the needs of their patients living with SCD. While 43% indicated understanding the needs of patients with SCD somewhat well, 29% reported understanding their needs very well. Nearly 3 out of 10 (29%) healthcare providers reported not understanding their patients' needs. See Figure 4.

Figure 4: Healthcare Provider Understanding of Needs of Patients with SCD (*n* = 497)

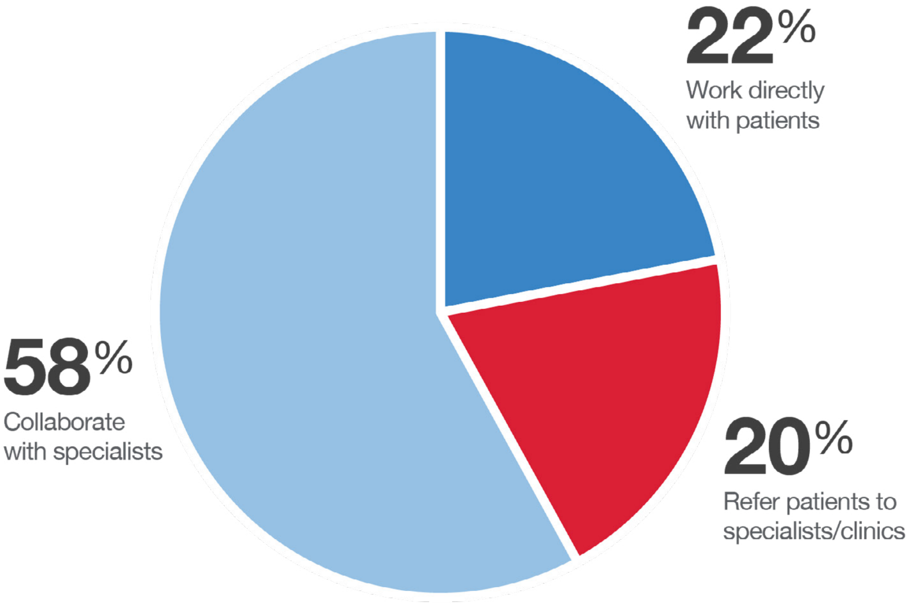


S9. How well do you understand SCD and the needs of patients living with the condition? [1-5 Likert Scale]

Role in Helping Patients Manage their SCD

Over half (58%) of the healthcare providers reported collaborating with SCD specialists to support patients in managing their SCD. Twenty-two percent of healthcare providers worked directly with patients to manage their patients' needs. One out of 5 (20%) reported referring patients to specialists or specialty clinics to help them manage their condition. See Figure 5.

Figure 5: Healthcare Provider Role in Managing Needs of Patients with SCD (*n* = 497)

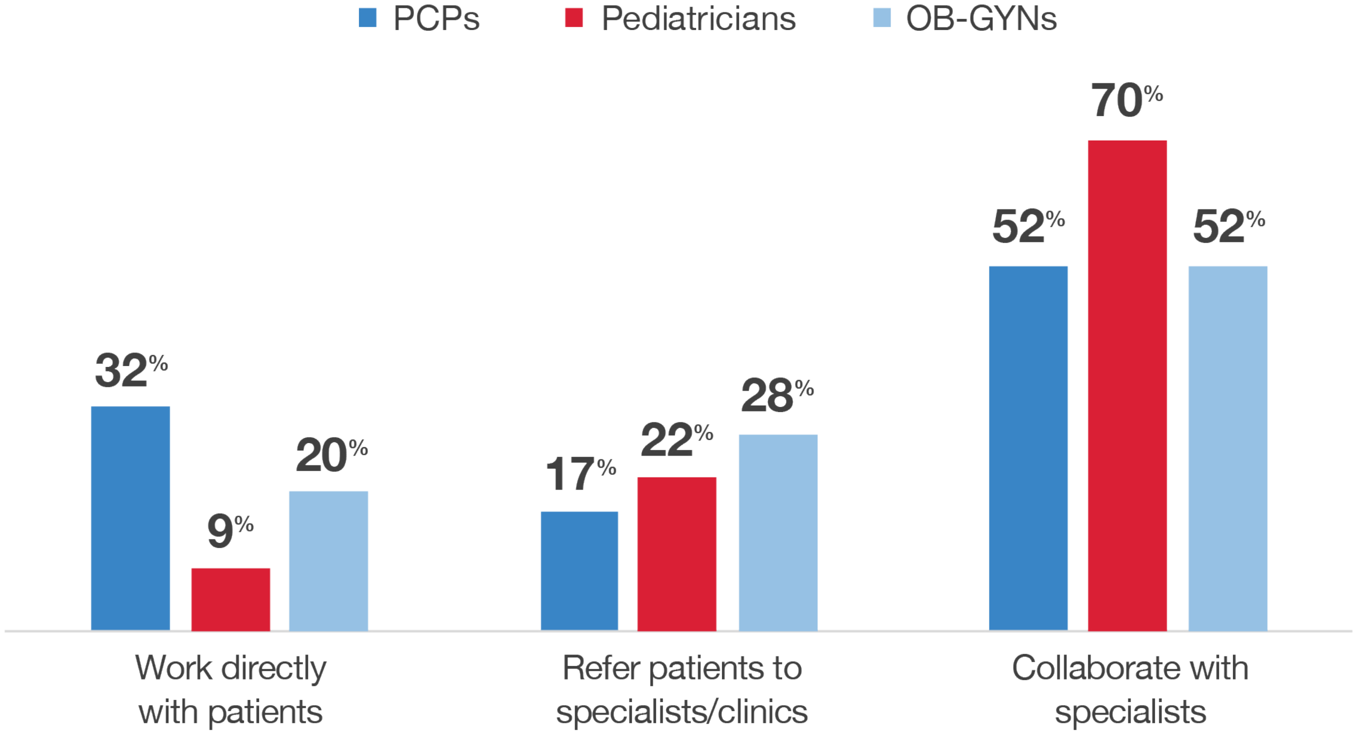


Q2. What is your role in helping patients manage their sickle cell disease? [Single select]

Figure 6 provides additional detail on how each healthcare provider type reported helping patients with SCD manage their condition. Seventy percent of pediatricians reported collaborating with specialists, compared to 9% who reported working directly with patients with SCD. Fifty-two percent of both PCPs and OB-GYNs reported collaborating with specialists, compared to 32% and 20%, respectively, who work with patients directly.

Figure 6: SCD Management by Healthcare Provider Type (*n* = 497)

(PCPs: *n* = 256, Pediatricians: *n* = 187, OB-GYNs: *n* = 54)

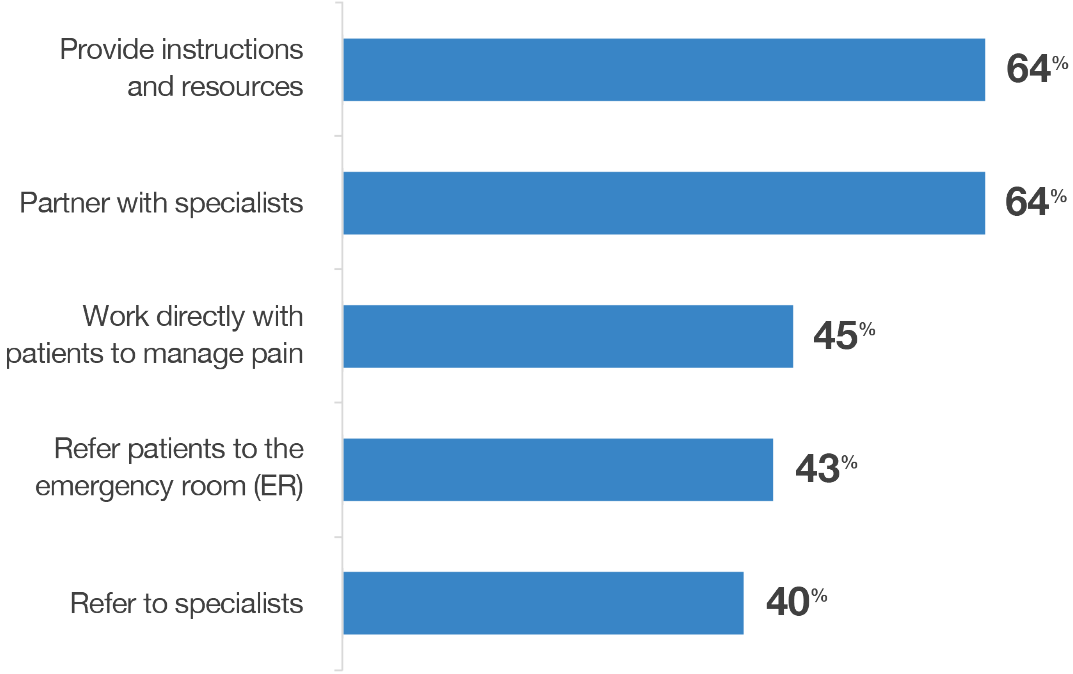


Q2. What is your role in helping patients manage their sickle cell disease? [Single select]

Healthcare Provider Role in Helping Patients Manage a Pain Crisis

When helping patients with SCD manage a pain crisis, healthcare providers tend to provide instructions and resources (64%), partner with specialists (64%), or work directly with patients to manage pain (45%). See Figure 7.

Figure 7: Healthcare Provider Role in Managing Pain Crises for Patients with SCD (*n* = 497)

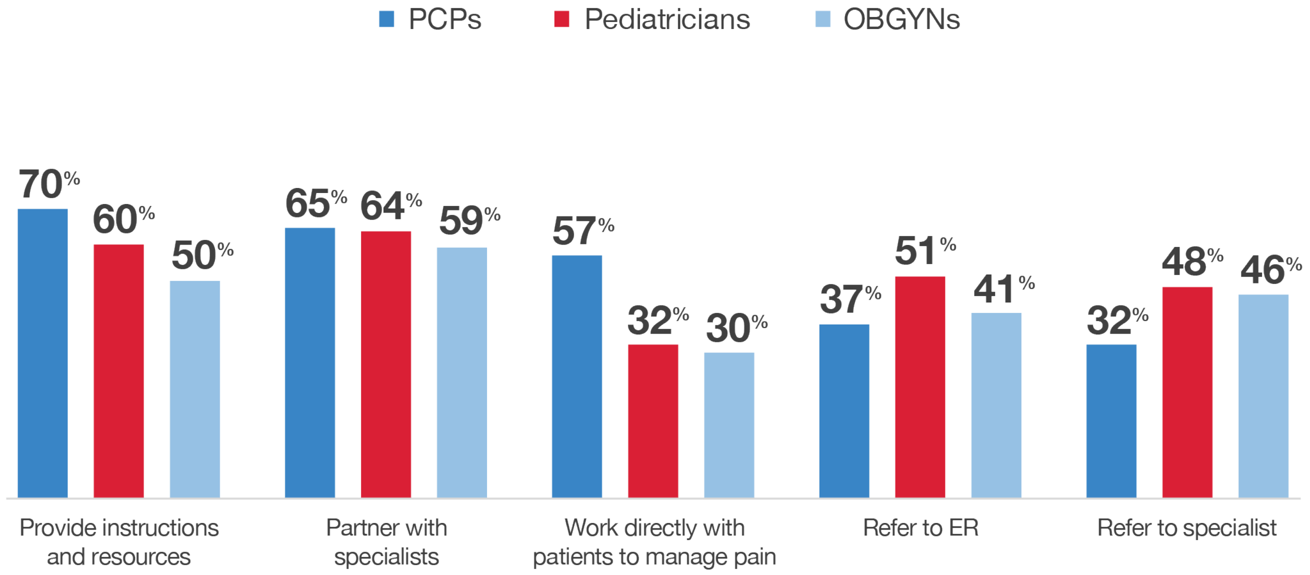


Q5. What is your role in helping patients manage a pain crisis? [Multi-select]

Fifty-one percent of pediatricians referred patients to the ER during pain crises, compared to 37% of PCPs and 41% of OB-GYNs. Alternatively, 57% of PCPs reported working directly with patients to manage pain, compared to 30% of OB-GYNs and 32% of pediatricians. See Figure 8.

Figure 8: Role in Managing Pain Crises for Patients with SCD by Healthcare Provider Type (*n* = 497)

(PCPs: *n* = 256, Pediatricians: *n* = 187, OB-GYNs: *n* = 54)



Q5. What is your role in helping patients manage a pain crisis? [Multi-select]

Of the 130 healthcare providers who reported having very high SCD knowledge, 35% referred patients to SCD clinics or specialists and 42% referred patients to emergency care during a pain crisis. See Figure 9.

Figure 9: Healthcare Provider Role During Pain Crises Based on Very High SCD Knowledge (*n* = 130)

82%
Provide instructions and resources on how to prevent and manage pain crises

75%
Partner with specialists to help patients manage pain during a crisis

65%
Work directly with patients to help them manage pain during a crisis

35%
Refer patients to SCD clinics or specialists during a pain crisis

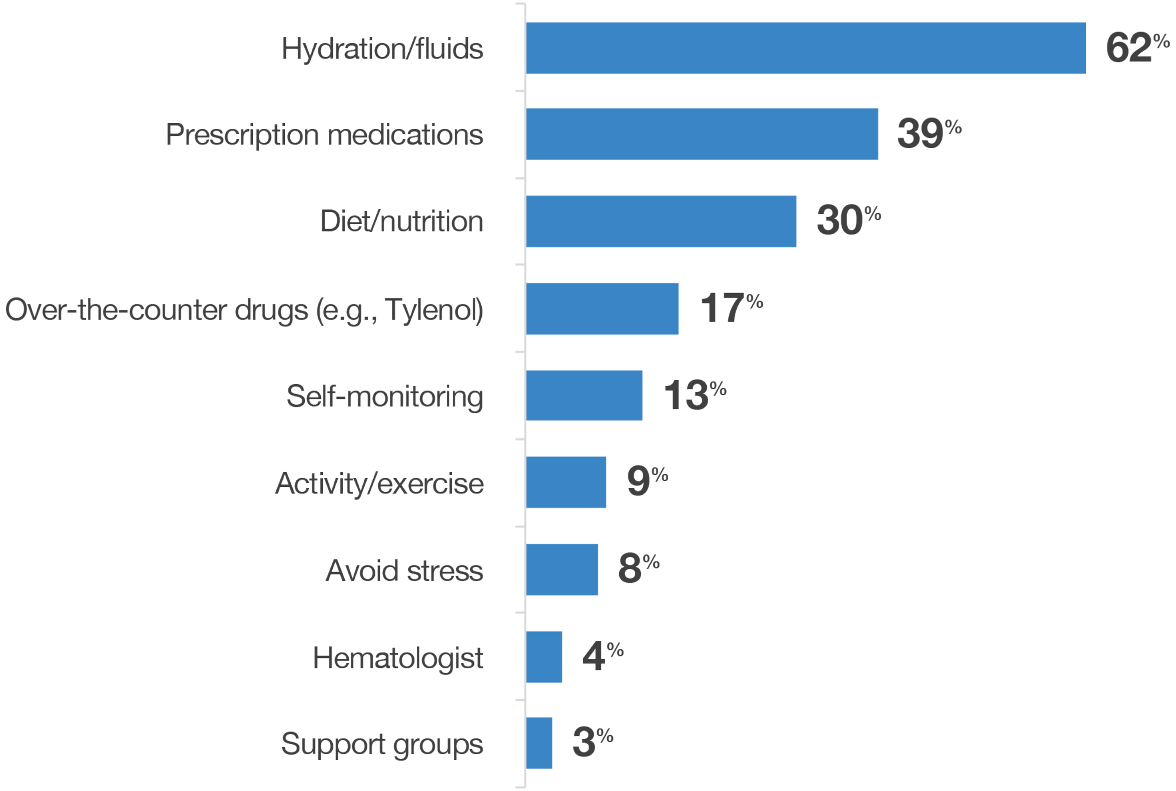
42%
Refer patients to emergency care during a pain crisis

Q5. What is your role in helping patients manage a pain crisis? [Multi-select]

Resources Shared with Patients to Help Prevent Pain Crises

Healthcare providers reported sharing resources with patients to help prevent pain crises. The most common resources and instructions healthcare providers shared included hydration/fluids (62%), prescription medications (39%), and diet/nutrition (30%). See Figure 10. Specifically, respondents shared they discussed “the importance of daily fluid intake and ensuring hydration status,” “ensuring patients were on medications if indicated, such as hydroxyurea, etc.,” “scheduling their over-the-counter medications as opposed to taking them on an as-needed basis to ensure consistent lowering of pain severity throughout the crisis episode,” and “advocating for exercise and staying active” with patients.

Figure 10: Resources and Instructions that Healthcare Providers Regularly Shared with Patients with SCD (*n* = 497)

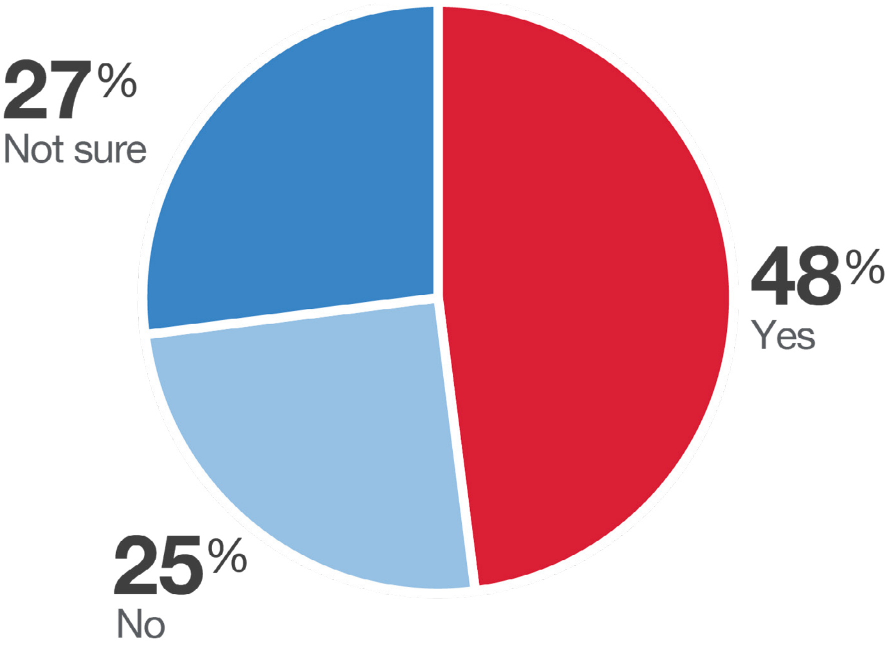


Q6. What resources or instructions do you share with patients living with sickle cell disease to help them prevent a pain crisis? Examples might include nutrition guidance, hydration, self-monitoring, over-the-counter medications, etc. Please be as specific as possible. [Open-ended response]

Healthcare Provider Knowledge of Current Treatment Options, Including Gene Therapy

Less than half of healthcare providers (48%) reported feeling knowledgeable about current SCD treatment options. See Figure 11.

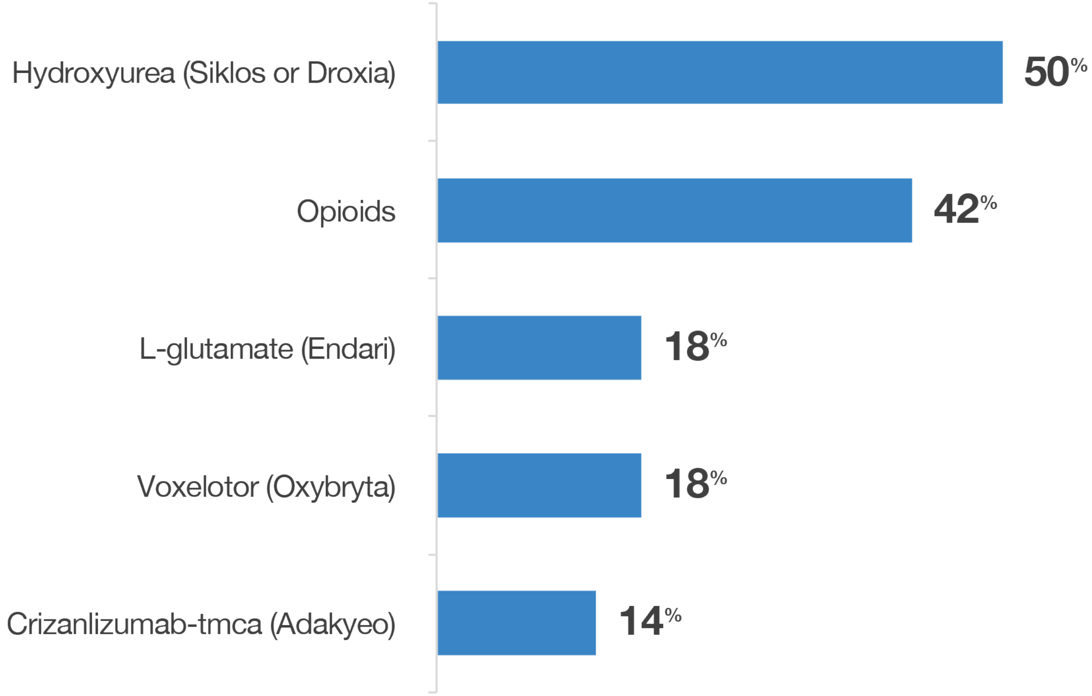
Figure 11: Do You Feel Knowledgeable About Current Treatment Options for Patients Living with SCD? (*n* = 497)



Q9. Do you feel knowledgeable about current treatment options for patients living with SCD? [Single select]

Healthcare providers most frequently reported prescribing hydroxyurea (50%) and opioids (42%) for SCD. Less than 20% of healthcare providers prescribed newer treatments for SCD, such as L-glutamate (18%), voxelotor (18%), or crizanlizumab-tmca (14%).[2] See Figure 12.

Figure 12: Most Frequently Prescribed SCD Treatment Options (*n* = 497)



Note: Data represent two top box scores of "very often" and "somewhat often."

Q10. How frequently do you prescribe the following treatment options for patients living with SCD? [1-5 Likert Scale]

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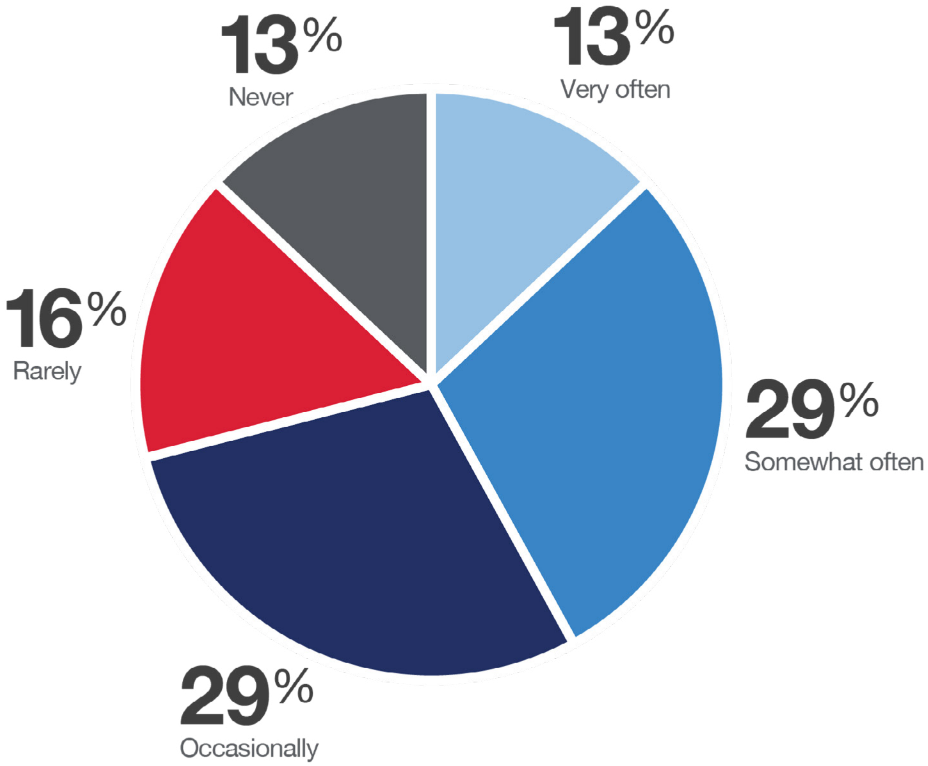
[2] At the time of this research, voxelotor was approved by the FDA for the treatment of SCD. It was voluntarily withdrawn from the market by the manufacturer in September 2024.

Opioid Management for Patients with SCD

Forty-two percent of respondents prescribed opioids for pain management often, with 13% prescribing it very often and 29% prescribing it somewhat often. See Figure 13.

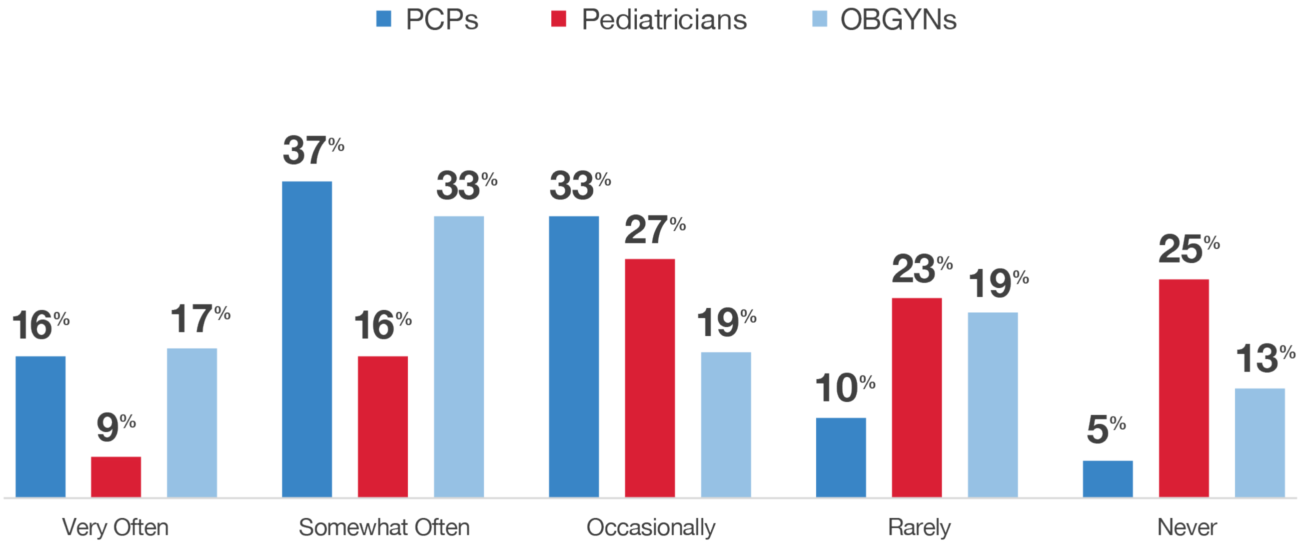
Figure 13: Frequency of Prescribing Opioids for Patients with SCD (*n* = 497)



Q10. How frequently do you prescribe the following treatment options for patients living with SCD? [1-5 Likert Scale]

When stratified by healthcare provider type, a higher percentage of PCPs and OB-GYNs prescribed opioids compared to pediatricians. Sixteen percent of PCPs prescribed them very often and 37% prescribed them somewhat often, whereas 17% of OB-GYNs prescribed them very often and 33% prescribed them somewhat often. Nine percent of pediatricians prescribed them very often and 16% prescribed them somewhat often. See Figure 14.

Figure 14: Frequency of Prescribing Opioids by Healthcare Provider Type (*n* = 497)



Q10. How frequently do you prescribe the following treatment options for patients living with SCD? [1-5 Likert Scale]

Although nearly all (93%) healthcare providers reported that an unmanaged pain crisis increases the risk of stroke, ER visits, and hospitalizations, more than half had concerns about the available treatment options. See Figure 15.

- Approximately two-thirds of healthcare providers reported concern about prescribing opioids too often (69%), that they found it difficult to know how much pain their patients with SCD were experiencing (63%), and that they recognize chronic pain is a common health issue of SCD (62%).
- Nearly three-quarters (73%) of the respondents agreed that opioids are appropriate for the treatment of acute pain crises.
- Nearly half (47%) of the respondents reported a need for better guidelines to help them manage patients' SCD pain crises.

Figure 15: Healthcare Provider Agreement with Pain Management Statements (*n* = 497)

93%
Agree that an unmanaged pain crisis increases the risk of stroke, ER visits, and hospitalizations

73%
Agree that opioids are appropriate for the treatment of acute pain crises

69% Worry about prescribing opioids too frequently for patients with SCD

63%
Agree that it is difficult to know just how much pain a patient with SCD is in

62%
Feel that chronic pain is an issue for most of their patients with SCD

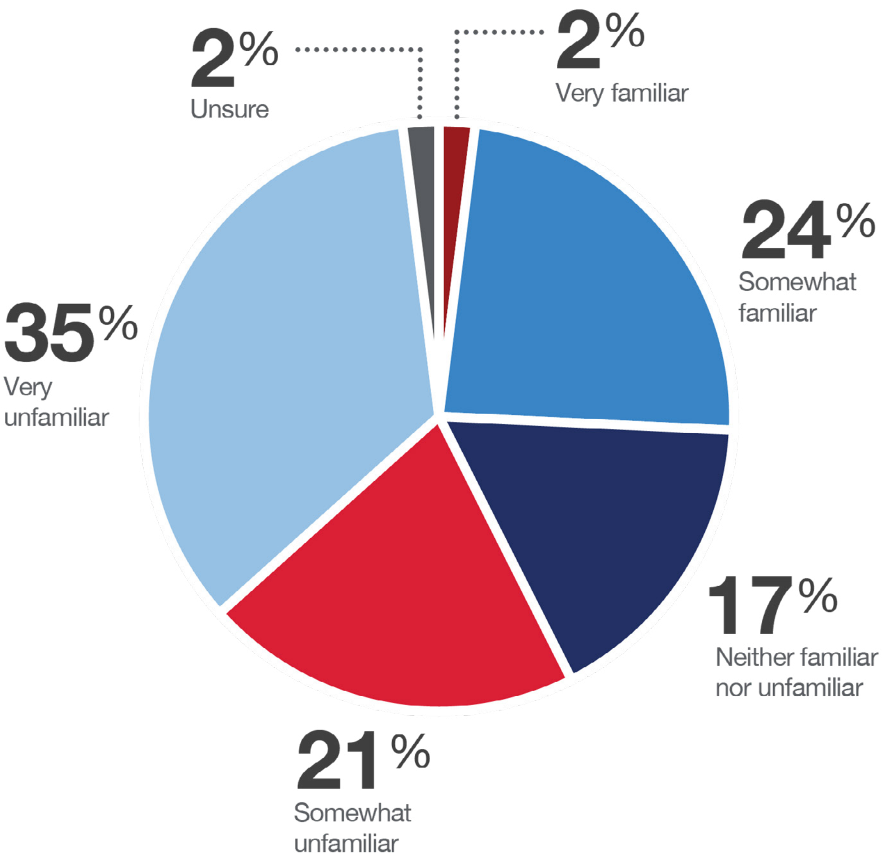
47% Feel that there is a need for better guidelines to help clinicians manage pain crises

Note: Data represent two top box scores of "strongly agree" and "somewhat agree."

Q7. Please give your level of agreement with each of the following statements, thinking specifically about your patients living with sickle cell disease and the care you provide to them. [1-5 Likert Scale]

Healthcare providers were also asked about their familiarity with gene therapies. Approximately 1 out of 4 (26%) were familiar with SCD gene therapies under development, with 2% saying they were very familiar and 24% saying they were somewhat familiar.[3] More than half (56%) were unfamiliar, with 21% saying they were somewhat unfamiliar and 35% saying they were very unfamiliar. See Figure 16.

Figure 16: Familiarity with SCD Gene Therapies Being Developed (*n* = 497)



Q15. How familiar are you with gene therapies that are being developed for patients living with SCD? [1-5 Likert scale]

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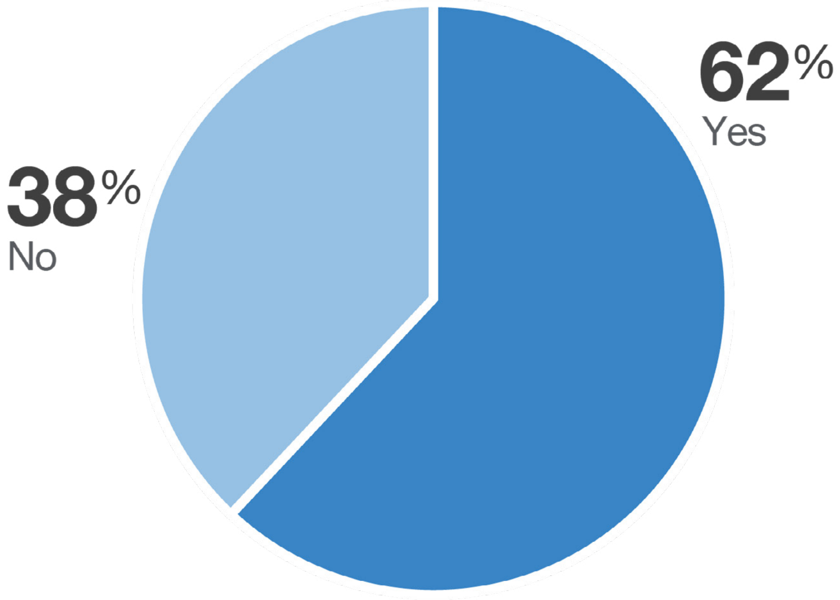
[3] At the time of this research, cell-based gene therapies for the treatment of SCD were not approved by the FDA. Two gene therapies for the treatment of SCD were approved by the FDA in December 2023.

Clinical Trials

More than 3 out of 5 (62%) healthcare providers reported that they refer patients to specialists to learn more about SCD clinical trials. See Figure 17. Healthcare providers also sought additional information to share with their patients, including:

- More information about current trials and eligibility to be accepted into a trial
- Guidance on where to direct patients to learn more about clinical trials and resources to help them understand what to expect when participating in a clinical trial
- Summary sheets about clinical trials in plain language to share with patients
- Updated information on availability of local clinical trials

Figure 17: Have You Referred Patients to a Specialist to Learn More About SCD Clinical Trials? (*n* = 497)



Q13. Have you referred patients to a specialist to learn more about SCD clinical trials? [Single select]

Resources

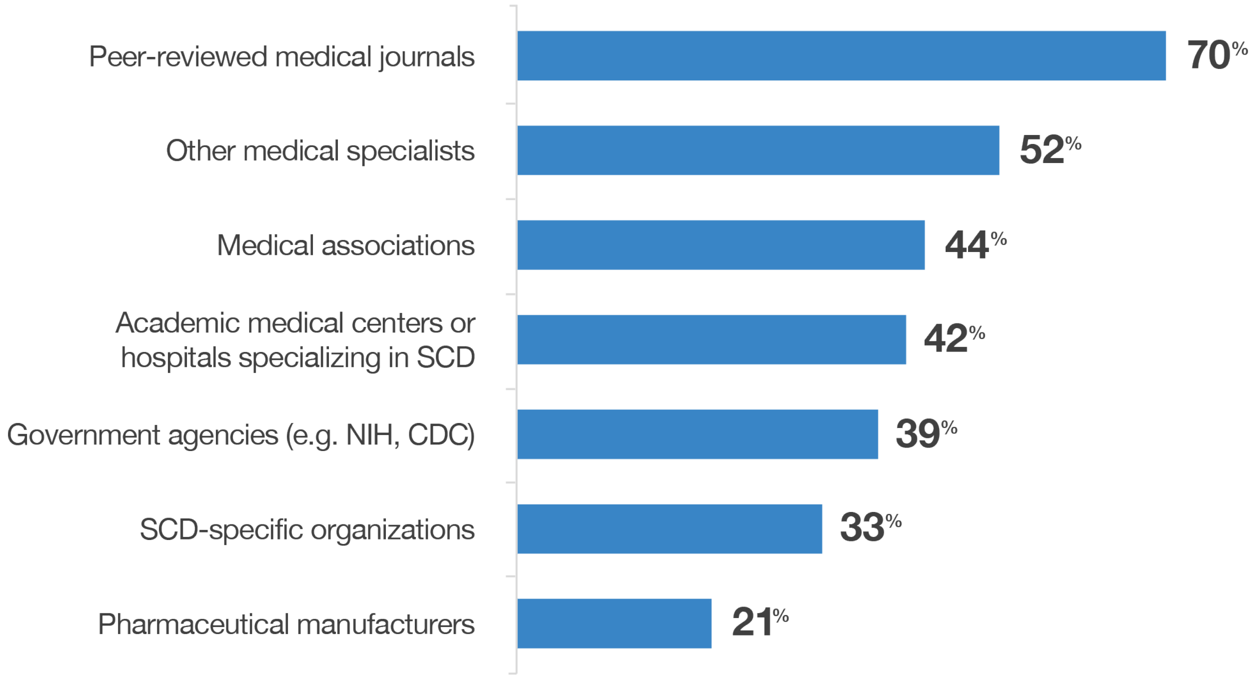
Respondents considered professional associations (77%), medical societies (69%), and government agencies (62%) to be the most reliable sources of information about SCD. See Figure 18.

Figure 18: Organizations Seen as the Most Reliable Sources of Information About SCD (*n* = 497)

Q16. What organizations do you trust as a reliable source of information about sickle cell disease? [Multi-select]

The three most frequently cited resources that healthcare providers used to stay up to date on the latest SCD treatments were peer-reviewed medical journals (70%), other medical specialists (52%), and medical associations (44%). SCD-specific organizations (33%) and pharmaceutical manufacturers (21%) were the two least cited resources. See Figure 19.

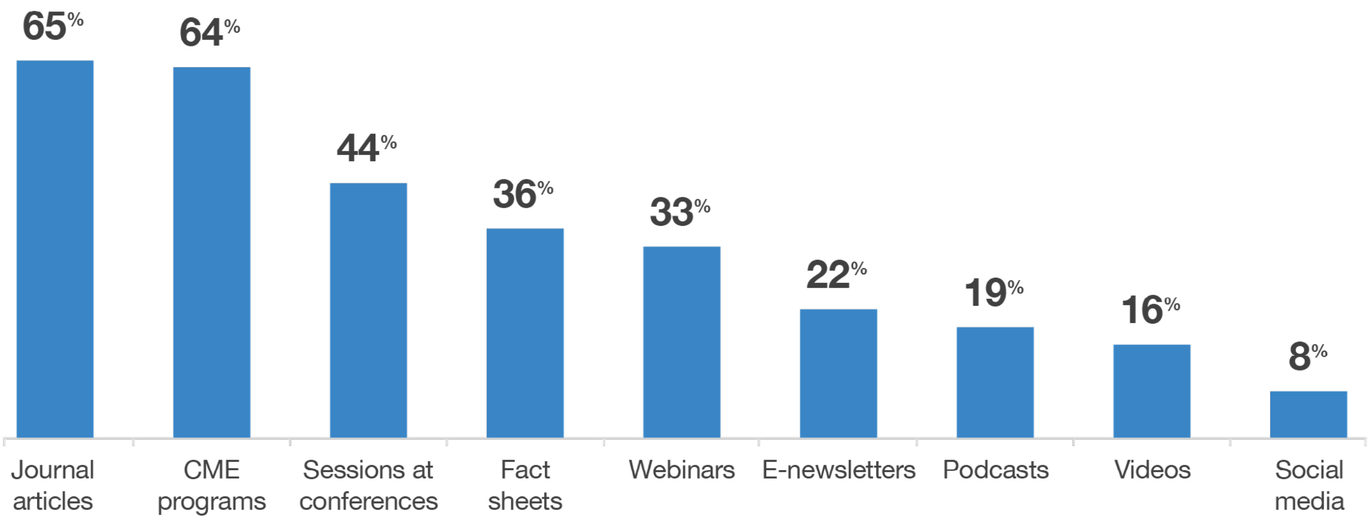
Figure 19: Resources Used to Stay Up to Date on Latest SCD Treatments (*n* = 497)



Q17. What resources do you use to stay up-to-date on the latest treatment information for sickle cell disease? [Multi-select]

Respondents indicated that their preferred formats for receiving information to improve their knowledge about SCD were journal articles (65%), CME programs (64%), and sessions at conferences (44%). See Figure 20.

Figure 20: Preferred Format for SCD Education Resources (*n* = 497)



Q18. What formats do you prefer for receiving information to help improve your knowledge about SCD? Please select all that apply. [Multi-select]

Desired Information or Additional Resources

Eighty-four percent of healthcare providers strongly agreed or somewhat agreed they need more information on prescribing new medications for patients with SCD.

> **“Clearer outlines of treatment regimens and more information about the newer treatments, including gene therapy.”** — *Participant*

> **“I wish I knew how to prevent pain, how to know when opioids are the right choice, and who is at risk for overuse.”** — *Participant*

> **“A general primary care update resource (maybe like an American Academy of Family Physicians page) for general disease management, as well as guidance on what primary care should be responsible for and looking out for in between hematologist appointments.”** — *Participant*

Q20. What information or resources do you wish you had – or know that your peers would benefit from – when managing or treating patients living with sickle cell disease? [Open-ended response]

CONCLUSION

PCPs, pediatricians, and OB-GYNs play key roles in caring for patients with SCD. Although these healthcare providers regularly see patients with SCD and have knowledge about SCD care and treatment options, respondents acknowledged gaps in their awareness, understanding, and comfort with recommending these options. Specifically, healthcare providers cited a need for more information and education about new gene therapies and guidance regarding medications such as opioids for pain management. This survey highlights crucial opportunities to engage and support the broader healthcare provider community to improve care for patients with SCD. NHLBI’s *BDDEP* and CVS Health® are using these findings to develop and refine educational resources for healthcare providers and the SCD community.