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Pain communication for children, adolescents, and adults with sickle cell disease: A scoping review

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Abstract

Sickle cell disease (SCD) causes severe pain from vaso-occlusive episodes and other complications. Communication about pain among individuals with SCD, caregivers, and clinicians can be complex, challenging, and sometimes contentious. Prior research has shown that people with SCD feel unheard by clinicians and that pain is undertreated. However, the literature on pain communication in SCD has never been synthesized, and its impact on patient outcomes remains unclear. This study aimed to characterize the literature on pain communication in SCD and identify evidence gaps. We conducted a scoping review of literature examining how people with SCD, caregivers, and clinicians communicate about pain. We searched PubMed, Embase, Web of Science, CINAHL, PsycINFO, and Cochrane Library for articles published before May 2026. We narratively synthesized results, informed by the Pain Assessment as a Social Transaction Model. We screened 5451 studies and included 242 (37% observational, 33% qualitative, 7% experimental/interventional). We found that pain communication is shaped by patient factors (developmental stage, prior experiences, communication and coping skills) and clinician factors (SCD knowledge/training, attitudes about SCD). Patient-clinician interactions were characterized by low levels of trust, empathy, and collaboration. Poor communication was associated with inadequate pain management, lower satisfaction, delayed care-seeking, hospital self-discharge, reduced trust, and adverse psychological consequences. Few interventions targeted pain communication. Challenges in patient-clinician pain communication in SCD are well documented and associated with serious consequences, but efforts to address them remain limited. Future research should prioritize theory-informed interventions supporting effective pain communication among individuals with SCD, caregivers, and clinicians.

Introduction

Sickle cell disease (SCD) is one of the most common genetic disorders worldwide, affecting nearly 8 million children, adolescents, and adults.[1] It is associated with significant morbidity and early mortality, with a life expectancy in the United States (US) of 52.6 years, more than two decades lower than the general population.[2–6] The mortality burden is even greater in lower-income countries with a high prevalence of SCD.[1] Pain is a hallmark experience of people living with SCD and affects every aspect of life, from family and relationships to school and work.[4] People with SCD experience severe acute vaso-occlusive pain episodes (VOEs), which often begin in early childhood, and many individuals also develop chronic pain.[7] Though people with SCD manage most of their pain at home,[7] severe episodes require urgent evaluation and treatment with intravenous opioids in the Emergency Department (ED) or inpatient hospital setting.[5]

Pain communication in SCD is complex and challenging. SCD pain is subjective, without laboratory, radiographic, or vital sign markers that can reliably indicate the presence of a VOE. Furthermore, the SCD pain experience is complicated by intersecting layers of bias related to race, opioid use, and the SCD diagnosis itself.[8–10] People with SCD describe feeling unheard, disbelieved, and disrespected by clinicians. [11–16] Despite these well-documented challenges, the specific ways in which pain communication breaks down remain poorly understood, as do opportunities to improve communication.

The Pain Assessment as a Social Transaction (PAST) model has been previously used to understand SCD pain communication.[16–19] The model conceptualizes pain management as a multistep process between patients and clinicians: (1) patient's pain experience, (2) patient's verbal and nonverbal pain expression, (3) clinician's pain assessment, (4) clinician's judgement

of pain, and (5) clinician's intervention. The process is influenced by patient factors (e.g., age, culture, prior experiences) and clinician factors (e.g., workload, training, personal beliefs or biases). The PAST model provides a useful framework for examining the complex dynamics of pain communication in SCD.

Despite wide recognition of the challenges surrounding pain communication in SCD, the existing literature on this topic has not been mapped. Furthermore, it is unclear how pain communication impacts patient and clinician behaviors and outcomes. The aim of this scoping review is to examine what is known about pain communication in people with SCD and identify evidence gaps.

Methods

To examine the evidence base for pain communication in SCD, we conducted a scoping review in accordance with the Joanna Briggs Institute guidance.[20] Methods are reported using the PRISMA Extension for Scoping Reviews checklist (PRISMA-ScR; **Supplemental Material 1**).[21] The scoping review protocol was registered on the Open Science Framework.[22]

Eligibility Criteria

We included all types of peer reviewed studies and excluded conference abstracts and non-peer-reviewed publications, including dissertations. Studies from all countries were eligible, but due to resource constraints, we included only English-language studies. No date restrictions were applied to the search. We used the Population, Concept, and Context framework (PCC) to outline inclusion and exclusion criteria (**Supplemental Material 2**).

Population. We included studies of people with SCD of all ages, including children, adolescents and young adults (AYA), and adults. We also included studies focused on caregivers of people with SCD and clinicians providing medical care for people with SCD.

Concept. We included studies that provided insight into communication about any type of SCD-related pain (not limited to VOE). Studies that described instrument development or validation were included if they discussed how well the measure captured the SCD pain experience, while studies reporting only psychometric data without additional commentary were excluded.

Context. We included studies of people with SCD in all contexts, including inpatient, ED, clinic, and home or community settings.

Search Strategy

Our search strategy (**Supplemental Material 3**) was developed in collaboration with a research librarian (CW). We searched PubMed, embase, Web of Science, CINAHL, APA PsycINFO, and Cochrane CENTRAL. The initial search was completed on December 10, 2024, and updated on May 27, 2026.

Study Selection

All results were loaded into Covidence,[23] a web-based platform that streamlines literature reviews, and duplicates were automatically detected and deleted. Title and abstract screening was conducted independently by two reviewers for each study, selected from a pool of five reviewers (MRA, MD, PT, MM, AH). Disagreements were resolved by a third reviewer. Full text review was also conducted independently by two reviewers, with disagreements resolved by consensus.

Reasons for excluding full text studies were recorded (**Figure 1**). References from the included studies and articles citing the included studies were also loaded into Covidence and screened by the primary author (MRA).

Data Extraction

The data extraction form was developed using Covidence by the primary author (MRA) and pilot tested by two additional reviewers (MD, PT; **Supplemental Material 4**). Data extraction was completed by one reviewer per study, selected from a pool of four reviewers (MRA, MD, PT, AH). All extracted data were subsequently checked for accuracy and completeness.

Data Analysis

Descriptive statistics were calculated using Microsoft Excel and figures were developed using Microsoft Office and R Studio.[24] The exact McNemar test was used to assess for differences in the number of studies examining patient- versus clinician-level communication factors. For studies that enrolled participants with SCD, participant age groups (pediatric, 0-17 years; AYA, 10-24 years; adult, ≥18 years) were estimated using a standardized strategy developed by the reviewers (**Supplemental Material 5**). We used the World Health Organization definition for the AYA age range.[25] The study findings were synthesized and reported narratively, using the PAST model[19] as a framework for organizing the components of the pain communication process.

Results

We screened titles and abstracts of 5451 studies, completed full text review for 575, and included 242 studies (**Figure 1**). Characteristics of included studies are shown in **Table 1** and the most pertinent studies on SCD pain communication (identified by reviewer consensus) are shown in **Table 2**. The list of all included studies is shown in **Supplemental Material 6**.

Most included studies were from the US (74.0%) and the United Kingdom (UK; 11.2%) with 12 other countries represented (2.1% Africa, 3.3% Middle East, 0.4% South Asia), and 5 studies conducting comparisons of multiple countries. The number of studies about pain communication increased over time, with 76.9% published since 2010 and 40.5% published since 2020. Most studies were observational (37.2%) or qualitative (33.0%) with only 6.6% experimental or interventional studies. Most studies (93.4%) discussed communication about acute VOE pain and 39.7% discussed chronic pain. A minority of studies discussed communication about other pain types, including leg ulcers, priapism, menstruation and pregnancy, kidney disease, and venipuncture.

Of 242 included studies, 184 recruited participants for original data collection; 160 included people with SCD, 37 included caregivers, and 37 included clinicians, with 25% including multiple participant types (**Figure 2A**). Of the studies that recruited individuals with SCD, 118 recruited adults (≥18 years), 102 recruited AYAs (10-24 years), and 63 recruited children (0-17 years); most studies included multiple age groups (**Figure 2B**). The number of studies relevant to each component of the PAST model are shown in **Figure 3**. Patient factors and behaviors were examined in more studies (92.6%) than clinician factors and behaviors (63.2%, $p < 0.001$). Most studies (73%) described challenges or conflicts in pain communication, and nearly half (47%) described inadequate clinician knowledge or low adherence to evidence-based care.

Patient Factors Contributing to Pain Communication

Age, development, and caregiver role. Studies demonstrated that in preverbal children, parents and clinicians used nonverbal cues such as activity level, crying, and swelling to assess pain.[26–29] School age children could conceptualize their illness and describe pain intensity, location, quality, and impact on daily life.[30,31] They could distinguish between SCD-related pain and non-SCD pain[32] and use numeric pain scales by age seven.[33] Studies generally found moderate-to-high concordance between child and parent pain ratings.[30,34–36] However, one study reported moderate-to-poor concordance overall, with greater agreement among school age children (8-12 years) than younger children (5-7 years) and adolescents.[37]

Parents of children with SCD described extensive involvement with communicating pain to clinicians, advocating for effective pain care and medical workup, and protecting their child in the hospital.[38,39] As their children entered adolescence, many parents sought to foster independent communication skills.[16,40–43] However, some adolescents described feeling "suffocated" by continued parental involvement.[44] Other AYAs developed guilt about their parents' suffering and attempted to conceal the extent of their pain.[14,17,45]

As they entered adulthood, some individuals with SCD chose to keep their medical care private from their families, especially if conflicts arose around pain beliefs[46–48] or opioid use.[16,49] In other families, adults with SCD continued to receive invaluable support from parents, spouses, and other caregivers in advocating with clinicians.[39,50]

Cognition. Studies described how SCD-related cognitive impairments (from ischemic stroke, silent cerebral infarction, and other disease-related complications) could impact pain communication.[12,18,51] Cognitive dysfunction was proposed as a potential mechanism for worse

communication experiences among patients with SCD compared to other hospitalized African American patients,[12] and as a factor to consider when designing pain assessment tools.[51]

Emotion factors impacting communication. Studies described how the emotional experience of SCD pain influenced pain communication in the ED and hospital. Individuals with SCD experienced significant anxiety associated with hospitalization, often shaped by negative prior experiences.[13,44,52–57] They also described feelings of loneliness and social isolation,[58–60] anger,[14,44,57,61,62] and helplessness or loss of control,[14,15,62–64] and recognized that these emotions intensified their pain.[13,15,16,54,57,65,66] They described fears of sudden or unexpected death resulting from clinician errors[16,67], as well as fear of opioid side effects and addiction.[14,44,55,68,69] These emotional experiences shaped how individuals expressed their pain and interacted with clinicians, and added to their frustration with perceived gaps in clinician knowledge and delays in care.

Clinician Factors Contributing to Pain Communication

Training and SCD knowledge. Inadequate clinician knowledge about SCD pain care was identified as a barrier to effective communication.[54,55,70–76] Many individuals with SCD had experiences in which clinicians revealed a lack of understanding about SCD, such as asking how long the patient has had SCD (a lifelong genetic illness).[16,17,77] These experiences damaged patients' trust and discouraged further communication with these clinicians.

Attitudes, beliefs, and bias. Many studies described clinician attitudes, beliefs, and bias as factors influencing SCD pain communication. These attitudes and beliefs were measured in the ED, inpatient, and outpatient settings using the Positive Provider Attitudes toward Sickle Cell Patients Scale[78] and the General Perceptions About Sickle Cell Patients Scale (GPSCPS).[79–83] In

one recent study using the GPSCPS, nearly 40% of clinicians believed that more than 20% of patients with SCD exaggerate their pain, manipulate clinicians, and "seek drugs" when presenting to the hospital. Additionally, more than half of clinicians reported that fewer than 20% of patients with SCD were easy to empathize with.[83]

From the patient perspective, experiences of clinician stigma and bias were common.[10,50,60,72,73,84–89] People with SCD described racial discrimination and explicit comments from clinicians about opioid dependence, addiction, or "drug seeking." Studies also highlighted how the language surrounding SCD is deeply entrenched in stigma and bias,[90] with pejorative terms such as "frequent flyer," "drug seeker," "difficult patient," and "malingerer" disproportionately applied to individuals with SCD.[8,91–93]

Fewer studies directly examined how clinician attitudes, beliefs, and biases influenced pain communication or treatment. One study found that ED physicians who use the pejorative term "sickler" to refer to individuals with SCD demonstrated more negative attitudes toward this population and were 12% less likely to rapidly redose opioids as recommended by evidence-based guidelines.[94] In contrast, another study found that race-related implicit bias was common among clinicians, but did not appear to influence pain treatment plans.[95]

Systems-level factors. Contextual factors impacted how clinicians communicate with patients with SCD.[16] Clinician communication was rated more highly in pediatric versus adult settings, [60,65,96,97] at centers with specialty SCD care versus those without, [98,99] and in clinics and day hospitals compared to the ED.[39,70,100,101]

Patient Pain Experience and Expression

Describing pain. Many individuals with SCD found the pain "impossible to describe"[102] and impossible to understand for anyone who has not experienced it.[39,77] One qualitative study highlighted how people with SCD may express their pain using analogy or metaphor, or by personifying their pain with human characteristics, in an effort to verbalize their complex subjective experiences.[102] For example, individuals with SCD described their pain as "a scorpion that stings,"[102] "bones on fire,"[73] and "a knife being stabbed."[44] Children with SCD were able to articulate their pain from a relatively early age (6 to 13 years) with language such as "sticking me with 100 needles," "having a building fall on you" or "hitting with a hammer."[103]

Studies described how pain itself could impede communication.[16,66,104] Some individuals with SCD described not wanting to speak or be touched while experiencing pain[57] and the weakness or fatigue that accompanies VOEs.[14,16,33,39,47,76,105,106] The burden of explaining their symptoms was especially pronounced when clinicians were unfamiliar with the patient or their disease.[66] Two articles provided guidance on focused assessment of VOE pain to minimize patient burden in the acute period.[16,107]

Differentiating acute and chronic pain. Individuals with SCD felt confident in distinguishing between acute versus chronic pain based on the severity, location, duration, quality, responsiveness to medication, and impact on function.[60,64,66,89,102,105,108] They described chronic pain as typically less severe than acute pain, but as an inescapable experience[60,64,109] and "constant battle every day."[89] Children and AYA described the onset of chronic pain as either gradual ("it just slowly got worse and worse until I was having pain all the time") or sudden, following an acute VOE ("I went to the hospital for pain and it just never went away").[110]

Pain types. Most studies described VOEs or chronic pain, but some studies specifically examined pain associated with stem cell transplant,[68] priapism,[61,111] leg ulcers,[112,113]

menstruation and pregnancy,[50,96] dialysis,[114] and procedures.[115] Studies that focused on priapism and leg ulcers highlighted the shame and isolation associated with these disease complications. Studies that focused on menstruation and pregnancy identified intersecting pain disparities for women with SCD.

Patient-Clinician Interactions

Adults with SCD reported worse communication compared to a national samples of African American adults[12] and hospitalized adults in the US.[11] In one study, 50-58% of adults with SCD reported they were not always treated with respect and dignity in the hospital, that doctors and nurses did not give clear answers to questions, and that clinicians did not discuss their fears and anxieties.[11] Patient-clinician conflicts were common, particularly in the US. Sixty-six percent of surveyed adults in Baltimore reported at least one lifetime dispute with staff, compared to 39% of surveyed adults in London.[116] Overt altercations, including physical fights, were also described.[67,88,117,118]

Negative patient-clinician experiences were identified by both patients and clinicians as major barriers to effective SCD pain care. Adults with SCD listed prior negative healthcare experiences, clinician disbelief or dismissal, difficult communication, accusations of drug seeking, long wait times, and inadequate clinician knowledge about SCD as major barriers to pain care.[73,85,119,120] Conversely, perceived trust and respect by ED physicians were significantly associated with higher patient ratings of ED pain management.[121] Clinicians identified "patient behavior" as a leading barrier to effective SCD pain care, alongside concerns about addiction, SCD stigma, and provider attitudes and implicit bias.[85,93]

Several studies highlighted that effective patient-clinician communication could only occur when clinicians were present at bedside. Individuals with SCD reported that clinicians sometimes seemed to intentionally deprioritize their pain, avoid them, or delay administering pain medications,[15,39,41,63] leading to worsening pain.[13,104] Patient and clinician perceptions differed: in one study, nurses reported "continually" assessing patients' pain, whereas adults with SCD perceived that nurses "never" assessed their pain or did so only during rounds.[122]

Patient-clinician dynamics were described as most contentious for individuals with "extremely high hospital use" (EHHU), referring to the small population of patients with SCD who account for the majority of inpatient hospital stays.[60,64] In one qualitative study, individuals with EHHU described defensive or reactive behaviors toward clinicians, in contrast to more collaborative behaviors from those with low hospital use.[64] History of EHHU may bias clinicians against the patient; in one study, pediatric nurses recommended lower doses of pain medication for children with histories of frequent presentations.[123]

Trust, empathy, and respect. Among adults with SCD, higher ratings of clinician communication were associated with stronger trust in the medical profession.[124] However, numerous studies described patient experiences of having their pain invalidated or dismissed by clinicians.[13,16,39,41,50,54,55,57,59,63,64,72,88,104,125] Over half of adults with SCD reported experiences of ED clinicians disbelieving their pain.[71,126] Individuals with SCD also described being treated without compassion or empathy by clinicians.[13,16,39,41,59,60,87] Among adults with SCD, 46-49% reported that ED physicians "never" or "sometimes" seemed to care about them and 35-45% reported similar perceptions of ED nurses.[71,100,126] Additionally, 58% did not perceive ED clinicians as sympathetic or understanding.[70] Some individuals with SCD described particularly

disrespectful and dehumanizing interactions, such as being "treated like a dog" or told, "oh shut up! You're not that sick!"[39]

Relationships and collaboration. Multiple studies demonstrated how compassionate and collaborative clinicians could have a major positive impact in SCD care.[16,60,96] People with SCD wanted clinicians to validate their pain experiences,[72] provide comfort,[38] communicate honestly and openly,[72,87,127] and understand their life outside the hospital.[75,95,107,128,129] They appreciated patient-centered explanations[43] and prompt updates about any changes to the care plan[54] or delays.[43] They valued shared decision-making about pain management[54,59,69,104] and hospital disposition.[60,107,130] However, in one study, 86% of hospitalized adults with SCD felt insufficiently involved in decisions about their care.[11] Individuals with SCD identified an imbalanced power dynamic with clinicians[72,84,112] and perceived that clinicians felt threatened when patients made specific suggestions for pain treatment.[16,41,54,62,72,76,77,128,131]

Cultural influences on patient-clinician interactions. Several articles advocated for improved cultural competency, sensitivity, and humility to improve communication in SCD pain care.[50,75,78,93,127,129,132–137] However, one article noted that cultural competency "can be a dangerous thing" if it leads well-meaning clinicians to rely on "psychosocial clichés" when interacting with African American families.[138]

In comparing studies from different countries, experiences of perceived stigma, clinician disbelief, lack of compassion, poor clinician SCD knowledge, and inadequate pain care were present in Saudi Arabia,[139,140] India,[58] and Brazil.[61,86,141] Experiences of racism were particularly highlighted in Brazil.[141] Some studies identified differences in SCD communication across countries, such as stoic pain expression in Nigeria compared to the UK,[75] increased stigma in the US compared to Lebanon,[39] and more patient-clinician disputes in the US than the UK.[116]

Clinician Assessment, Judgment, and Intervention

Measurement systems. Several studies examined the benefits and limitations of using validated measures to assess SCD pain. A detailed review of SCD pain assessment measures is beyond the scope of this article and has published elsewhere.[115,142,143] The use of unidimensional numeric pain scales, such as the Numeric Rating Scale (NRS)[144] or Visual Analogue Scale (VAS)[145], was widely described, with strengths and challenges identified in the SCD context. Some individuals with SCD valued these scales because their widespread use fosters familiarity and consistency across clinicians, and their brevity makes them easy to use even during severe pain.[16,26,38,146–148] However, other studies noted that numeric pain scales can feel reductive or inadequate to patients with SCD and may be misleading for clinicians.[16,17,64,66,102,118]

Several articles proposed alternative approaches to better capture the complex SCD pain experience. Painimation is a digital pain assessment tool co-designed with individuals with SCD and other pain conditions that allows users to select abstract animations representing their pain.[149–151] The Youth Acute Pain Functional Ability Questionnaire (YAPFAQ), developed and validated in children and AYAs,[152,153] and the Functional Status Pain Assessment (FSPA) scale, developed for adults,[154] assess pain severity through self-reported functional status. The Body Posture Scale asks children with SCD to classify their pain using images depicting varying pain intensities.[155] Other approaches include asking children with SCD to draw their pain experiences[156,157] or assign colors to their pain.[30]

Challenges of SCD pain assessment. Clinicians found SCD pain assessment challenging.[158,159] Some clinicians described feeling "shut out" by reticent patients, although others found it "challenging and rewarding" to figure out how to build trust and connect.[76,83]

Most clinicians wanted to provide effective pain management[83,128] and felt distressed by providing inadequate pain relief or not meeting patients' expectations.[160] At the same time, they felt a "moral and legal obligation" to avoid the administration of unnecessary medications, particularly opioids, and this tension led to discomfort for clinicians.[54,137]

Clinicians and patients have shown discordant ratings of SCD pain. For adults with SCD, studies have found weak or nonsignificant correlations between physician and patient ratings of pain intensity, with physicians consistently rating patients' pain lower than patients themselves.[122,161,162] In one study, physician ratings of pain severity correlated with observable "pain behaviors," but patient self-ratings did not, suggesting that physicians relied more on visible behaviors than the patient's subjective report.[161] Among children and AYAs presenting to the ED with pain, numeric pain scores correlated with time to analgesia for children with long bone fractures but not for SCD pain, suggesting that clinicians weighed factors other than reported pain intensity when assessing the urgency of analgesia for SCD.[148,163] In contrast, one study found that physician pain ratings did correlate with the reports of children and AYAs with SCD and their parents.[36]

Interpreting pain cues. Clinicians identified "red flag" behaviors that made them question patients' subjective pain reports, including prior conflicts with staff, previous hospital self-discharge,[67,83,164] and perceived discrepancies between verbal pain reports and observed behaviors, such as appearing comfortable or changing behaviors when staff are present.[83] From the patient perspective, these behaviors often reflected patient expertise, pain coping strategies, or adaptation to prior healthcare experiences. Individuals with SCD sometimes requested or avoided specific medications based on prior VOE experiences, including knowledge of which medications and doses are most effective and which have caused adverse effects.[16,39,55] Requests

for additional medication or tampering with the patient-controlled analgesia pump were also described as responses to inadequate pain treatment, sometimes referred to as "pseudoaddiction."[60,67,165]

Individuals with SCD described using various strategies to cope with pain (breathing, humor, distraction, mindfulness, prayer, meaning-making), but recognized that clinicians might interpret these coping strategies as evidence of lower pain severity.[16,17,44,60,65,74,131] Based on prior experiences of having their pain underestimated or undertreated, some individuals with SCD felt the need to "perform" or visibly display their pain for clinicians.[16,54,159] They also described feeling compelled to dress up before going to the ED (to appear more credible)[68,131,166] or to dress more casually (to appear more uncomfortable).[54] Others tried to "be a good patient" by concealing their anger or frustration with the goal of receiving better care.[16,101]

Communication among clinicians. Communication across clinician role groups was identified as another source of frustration and barrier to effective SCD pain care. Communication gaps occurred between nurses and doctors[67,83] and between the generalist ED or inpatient team and the outpatient hematology team.[59,73,93,100,107,158] Many clinicians also expressed distress about witnessing biased pain care from other clinicians.[75,83,84,93,107,117]

Outcomes Associated with Pain Communication

Psychological harm. Individuals with SCD identified poor pain communication and disrespectful or dehumanizing clinician behavior as a source of significant and lasting harm. Qualitative studies captured these perspectives: "[there's an] eroding effect every time you're faced with a system that believes you are pretending"[55] and "the emotional humiliation that you have to endure because of pain you didn't ask for [...] stays with you your whole life."[16] Studies

also proposed that conflicts with clinicians could reinforce pseudoaddiction and "red flag" behaviors[60,67,165] and the "neural processes that lead to chronic pain."[53]

Pain outcomes. In the qualitative literature, people with SCD linked poor communication with clinicians to ineffective pain treatment.[15,17,54,76,87,88,125] Patients described sharing more details about their pain with clinicians they trust.[16] Conflicts with clinicians led to increased anxiety and distress, which exacerbated the pain experience.[63] Patients with stronger trust and therapeutic alliance with clinicians were more willing to try recommended treatments for pain such as buprenorphine.[167]

Two SCD-specific measures of patient satisfaction, the Adult Sickle Cell Quality of Life Measurement Information System Quality of Care (ASCQ-Me QOC)[168] and Satisfaction with Treatment for Pain Questionnaire (STPQ),[169] were used in the inpatient, ED, outpatient, and community settings.[71,85,97,100,169–171] These measures specifically included items assessing patient-clinician pain communication, including satisfaction with communication, comfort asking questions, involvement in decision-making, and whether clinicians believed patients' pain, listened carefully, treated them with courtesy and respect, and demonstrated care about the patient. Both measures were associated with pain outcomes: lower STPQ scores were associated with more frequent breakthrough pain, and lower ASCQ-Me QOC scores were associated with greater pain interference.[100,169] Patient satisfaction with pain care was also associated with pain intensity, time spent with tolerable pain levels, pain expectations, and optimal pain goals.[172]

Delayed care-seeking and premature discharge. Prior negative experiences with clinicians were associated with delays in seeking emergency SCD care, which could lead to dangerous delays in treatment of life-threatening disease complications.[54,55,71,126,166,170] In a multisite survey of AYA and adults with SCD, 52% indicated that prior negative ED experiences

had influenced their decision to avoid seeking care, and 67% reported that they delayed seeking care in the past 12 months.[100] Another study identified stigmatizing experiences or not being believed by doctors as the most common reasons that people with SCD delayed care-seeking.[173] Poorer communication with clinicians was also associated with greater likelihood of premature self-directed hospital discharge, which can lead to dangerous disease-related complications.[174]

Interventions to Improve Pain Communication

Communication training for patients. Two interventions aimed to improve communication skills among individuals with SCD. A randomized pilot study tested an intervention designed to reduce health-related stigma among AYAs with SCD by teaching assertive communication skills, compared with an attention control condition (life-review interviews). However, post-intervention health-related stigma scores were worse in the intervention group than the control group (mean score 92.6 versus 75.6, $p = 0.0085$).[175] Another pilot study assessed an intervention to train patients in using the Situation-Background-Assessment-Recommendation (SBAR) framework for communicating clinical information, using video vignettes simulating clinicians in the ED. Trained observers determined that participants used the SBAR framework correctly 72-95% of the time. Six of 10 participants reported that the SBAR training was helpful.[125]

Communication training for clinicians. A pre-post pilot study evaluated a communication and cultural awareness course for clinicians caring for individuals with SCD. Clinicians reported increased confidence in caring for patients with SCD at 3 and 6 months post-intervention ($p < 0.001$) and increased self-reported use of listening, empathy, and a nonjudgemental approach.[129]

Interventions to improve clinician attitudes. Haywood and colleagues developed an 8-minute video intervention featuring people with SCD describing the challenges they face when seeking pain treatment. In a randomized post-test-only study, inpatient nurses and resident physicians who viewed this video demonstrated decreased negative attitudes (difference in means = -8.9, 95% CI [-14.2,-3.6]), decreased endorsement of "concern-raising" behaviors (difference in means = -7.8, 95% CI [-13.1,-2.5]), and increased positive attitudes toward people with SCD (difference in means = 6.6, 95% CI [0.6,12.6]) compared to a control group.[79] Two other studies demonstrated similar effects of the same video intervention among ED clinicians[81] and pediatric clinicians[80]

Another intervention, tested in a randomized pilot trial, delivered a training aimed at improving implicit bias among pediatric clinicians compared to an educational control, and asked participants to select appropriate pain treatments in virtual patient vignettes. Most clinician participants (94.4%) showed a pro-White (versus Black) bias when viewing child faces in the Implicit Association Test. However, all clinicians rated the preferred treatment plans higher than the less-preferred alternative, without an effect of intervention or the virtual patient's race. [95]

Interventions to improve pain expression and assessment. Several studies have suggested that technology-enabled pain assessment tools could facilitate pain assessment for people with SCD, thus leading to improved pain outcomes. For example, the Painimation tool uses abstract animations to capture the subjective pain experience.[149–151] Several studies that used daily pain diaries or patient-reported pain outcomes reported greater patient self-awareness of their symptoms and improved communication with caregivers and clinicians.[31,146,176–178] Two studies implemented text message check-ins from clinicians triggered by patient-reported pain outcomes, and reported improved communication about symptoms.[176,179] A single-arm pre-post

study of music therapy for hospitalized patients with SCD suggested that the intervention increased patients' insight and facilitated verbal processing of their pain.[180]

Systems-level interventions. Another approach to improving patient-clinician communication is to implement standardized protocols to minimize clinician discretion and reduce potential conflicts.[107,181,182] One quality improvement initiative trained staff in guideline-concordant pain care and demonstrated improved patient satisfaction and perceived staff responsiveness.[183] Day hospitals (or infusion centers) offer an alternative to ED or inpatient care, allowing individuals with SCD to receive intravenous pain treatment in a specialized setting. Patients reported better communication at infusion centers than the ED due to continuity and rapport with staff, and staff expertise in SCD pain management.[16,39] Individualized pain plans embedded in the medical record provide guidance to ED and inpatient clinicians guidance on recommended pain treatments for each patient.[93,107,158,171,184] People with SCD reported that these plans reduced patient-clinician conflict by providing clinicians with an efficient, readily accessible source of information that they perceived as "legitimate," rather than relying on patients to convey their pain plans to potentially skeptical clinicians.

Discussion

To our knowledge, this is the first scoping review to assess the existing literature on SCD pain communication and identify evidence gaps. In this review, we used the PAST model to characterize each step of the pain communication encounter and identify patient- and clinician-level factors that influence communication. Overall, poor patient-clinician pain communication is widely recognized as a barrier to effective SCD pain care and a source of distress for both

patients and clinicians. However, primary literature examining clinical correlates of pain communication and developing interventions to improve pain communication are lacking.

Some components of the pain communication process are well developed in the literature, and others remain underexplored. The literature is rich in descriptions of patients' experiences seeking acute care for SCD pain and encountering clinician disbelief and dismissal, bias and stigma, and lack of SCD knowledge. These perspectives are critically important in amplifying the voices of a population that has endured centuries of poor treatment and inadequate medical care. However, the clinician experience of SCD pain communication—including clinicians' emotional state, social pressures, personal experiences, and other factors—is underdeveloped. Though there are data on clinician knowledge and attitudes toward people with SCD, the decision-making process by which clinicians translate patients' verbal and nonverbal cues into a pain management plan is still unknown. A clearer understanding of clinicians' experiences would inform interventions aimed at improving clinician pain communication behaviors.

Most of the included studies were published in the US and UK, despite the heavy burden of SCD in sub-Saharan Africa and South Asia.[1] The existing literature does suggest a surprising degree of commonality in experiences across countries, with evidence of opioid- and disease-related stigma, racism, dismissal of pain, long wait times, and inadequate clinician knowledge across contexts. However, there is also evidence of context-specific differences in pain expression and patient-clinician dynamics that would be valuable to explore in future studies. It is unclear whether the findings in this review will apply to people with SCD in other countries.

Mechanisms of pain communication in SCD. The specific behaviors and underlying mechanisms of patient-clinician pain communication remain understudied. Understanding the

"basic science" of communication—that is, how specific communication elements and mechanisms relate to outcomes—can guide development of interventions that promote evidence-based communication practices.[185] In oncology, for example, a robust body of communication research has supported the development of numerous interventions to improve patient-clinician communication.[186] A comparable evidence base does not exist for SCD. Furthermore, it remains unclear which insights and interventions from oncology and other fields could be applied to SCD, and which aspects of pain communication are unique to the SCD context.

The tools commonly used in communication research have rarely been applied to SCD. Communication researchers in oncology and other fields have traditionally audio- or video-recorded patient-clinician encounters to identify specific verbal and nonverbal behaviors. Among our included studies, only one used audio recordings of patient-clinician encounters.[187] Communication studies also have also relied heavily on simulated patient encounters to analyze, evaluate, and train clinicians in communication. These tools are also rarely used in SCD; only two pilot interventions used virtual patient vignettes[95,125] and three studies used role-play for evaluation or training.[123,129,183] The most effective methods for studying pain communication are evolving with changes in technology. Future studies of SCD pain communication may use artificial intelligence to analyze large samples of audio- and video-recorded encounters or use virtual reality to experimentally manipulate specific communication elements in virtual patient vignettes.[185]

Impact of patient-clinician communication on outcomes. The literature linking patient-clinician communication to patient and clinician outcomes is also underdeveloped. Despite a broad base of qualitative literature suggesting that poor communication leads to inadequate pain treatment, few studies have directly examined the link between communication and patient pain

outcomes. Also, despite numerous studies that have examined stigma, bias, and negative clinician attitudes in SCD, few studies have examined how these attitudes influence clinicians' behaviors and downstream patient outcomes. Generating additional data to link communication to outcomes would better characterize the impact of patient-clinician communication and the need for future interventions. Future prospective studies will measure communication elements and patient and clinician outcomes to clarify associations and untangle how these complex interactions influence SCD pain care.

Interventions to improve pain communication. Few interventions have been developed and tested to improve pain communication, despite widespread documentation of problematic patient-clinician dynamics. Evidence-based, theory-driven interventions to improve pain communication have the potential to improve patient outcomes including pain, mood and distress, quality of life, and trust, as well as hospital outcomes such as length of stay and hospital readmission rates. Individuals with SCD identify both interpersonal dynamics as well as clinician knowledge and accountability as barriers to high-quality pain care. Future interventions may be more effective if they improve clinicians' skills in both building strong interpersonal relationships with patients and managing SCD pain.

Patient-focused interventions aimed at improving skills in effective communication have also been proposed. Skill-building in communication and self-advocacy may be helpful as part of programs to facilitate transition from pediatric to adult SCD care. Dyadic communication interventions could help AYAs and their parents navigate the transition from parent-directed to AYA-directed communication. However, the qualitative literature reveals that many individuals with SCD already use many strategies to communicate their pain effectively to clinicians, and yet still experience pain dismissal or invalidation. Therefore, patient-focused interventions for

improving communication may be more effective if paired with strategies to modify clinician behavior.

Limitations

This scoping review focuses specifically on pain communication, and our search strategy, developed collaboratively with a research librarian, required that articles include terms for pain, communication, and SCD (**Supplemental Material 3**). However, we found that pain is such a pervasive component of the SCD experience that it may not be explicitly referenced in the title or abstract of studies in which pain communication is a central concept. For example, Haywood's article on "poor patient-provider communication and sickle cell disease"[12] was not identified in the original search because pain is not specifically referenced in the title or abstract, despite pain communication being a core topic of the paper. We subsequently identified the article through reference screening and included it in the review. Although we considered broadening the search strategy, we chose not to modify the search terms given our specific focus on pain communication. Instead, we mitigated this limitation by thoroughly screening the references of included studies and articles that cited them. However, it is possible that some relevant studies were missed.

We excluded studies published in languages other than English due to unavailability of services to translate these articles to English for review. Only 15 of 333 full text reports were excluded for this reason. Future reviews would include articles published in all languages to better capture the experiences of people with SCD across countries.

Conclusion

This scoping review maps the literature on pain communication in SCD and identifies evidence gaps. Problematic patient-clinician pain communication in SCD is well documented and associated with serious consequences, but efforts to address it have been limited. Future research may elucidate how specific elements in patient-clinician pain communication are linked to patient outcomes, and work to develop evidence-based interventions to improve patient-clinician pain communication.

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Figure 1. PRISMA 2020 flow diagram.

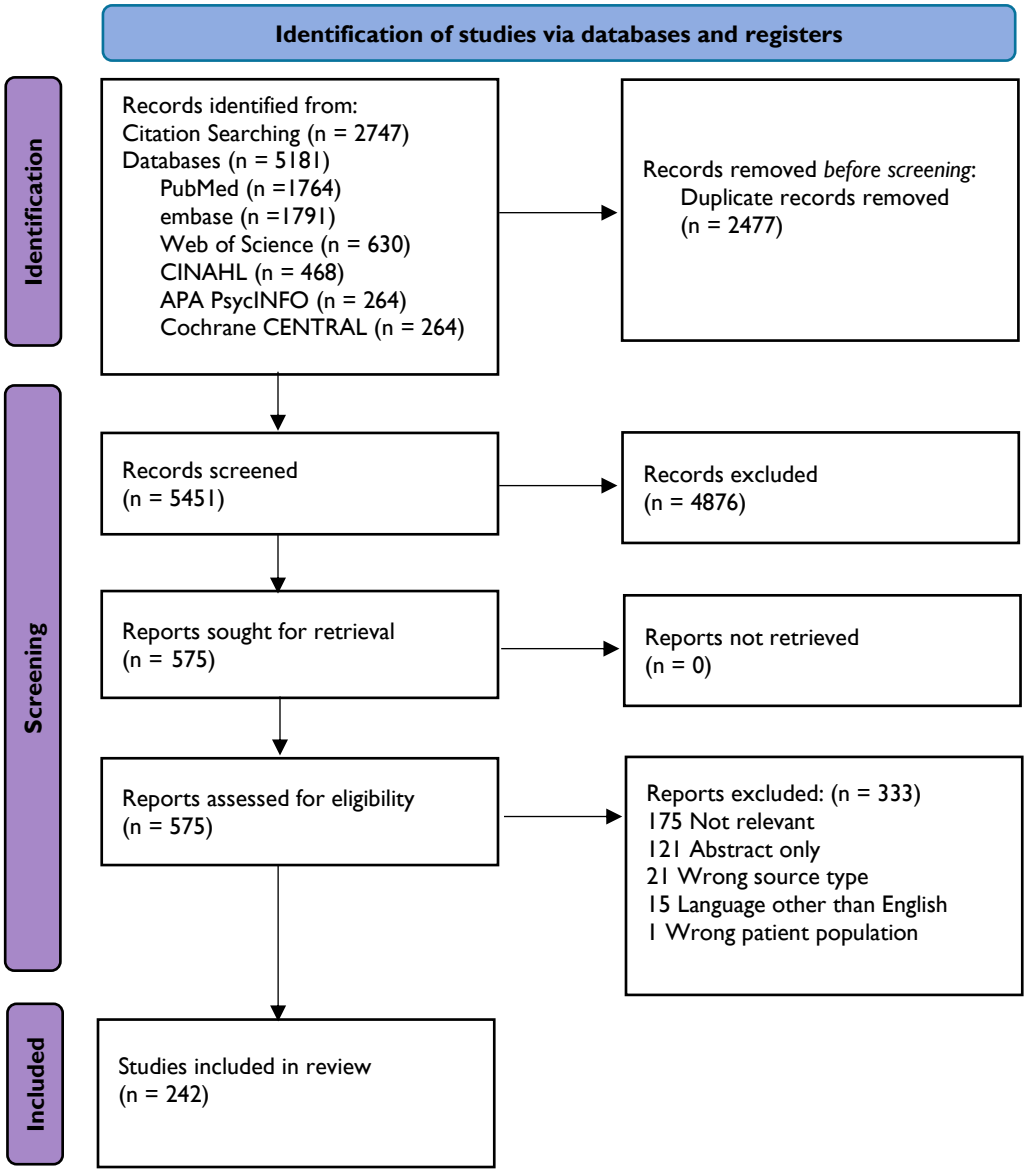


Table 1. Characteristics of included studies. *Country of origin:* country of participant recruitment or author affiliation. *Study design:* each article was assigned one design. *Pain type:* sickle cell-related pain types referenced; studies could reference multiple types. *Participants:* studies could include multiple role groups. *Pain communication setting:* location or context of pain communication; studies could reference multiple settings. *Participant age range:* pediatric (0–17 years), adolescent/young adult (10–24 years), or adult (≥18 years); studies could include multiple age ranges. *Participant enrollment setting:* studies could use multiple sites.

Characteristic	n (%)	Denominator
Country of origin		All included studies (N=242)
Brazil	7 (2.9)	
Canada	5 (2.1)	
France	2 (0.8)	
Ghana	2 (0.8)	
India	1 (0.4)	
Jamaica	1 (0.4)	
Lebanon	2 (0.8)	
Multiple countries	5 (2.1)	
New Zealand	1 (0.4)	
Nigeria	3 (1.2)	
Portugal	1 (0.4)	
Saudi Arabia	5 (2.1)	
Turkey	1 (0.4)	
United Kingdom	27 (11.2)	
United States	179 (74.0)	
Publication Year		
1989-1999	20 (8)	
2000-2009	36 (15)	
2010-2019	88 (36)	
2020-May 2026	98 (40)	
Study Design		All included studies (N=242)
Experimental/Interventional Study	16 (6.6)	
Expert Opinion or Commentary	28 (11.6)	
Observational Study	90 (37.2)	
Other	11 (4.5)	
Qualitative Research	80 (33.0)	
Review Article	17 (7.0)	
Pain Type		All included studies (N=242)
Acute/Vaso-occlusive	226 (93.4)	
Chronic	96 (39.7)	
Leg ulcers	12 (5.0)	
Neuropathic	11 (4.5)	
Priapism	6 (2.5)	
Procedural/Surgical	2 (0.8)	
Other	9 (3.7)	
Unspecified	6 (2.5)	

Participants		Studies enrolling participants (n=184)
People with SCD	160 (87.0)	
Caregivers	37 (20.1)	
Clinicians	37 (20.1)	
Pain Communication Setting		Studies enrolling participants (n=184)
Clinic/Community only	62 (33.7)	
ED/Inpatient only	55 (29.9)	
Both ED/Inpatient and Clinic/Community	64 (34.8)	
Other	3 (1.6)	
Participant Age Range		Studies enrolling individuals with SCD (n=160)
Pediatric (0-17 years)	63 (39.4)	
Adolescent/Young Adult (10-24 years)	102 (63.8)	
Adult (≥18 years)	118 (73.8)	
Participant Enrollment		Studies enrolling individuals with SCD (n=160)
Clinic	110 (69)	
Sickle Cell Groups/Community	35 (22)	
ED/Inpatient	30 (19)	
Mail, Email, Telephone	25 (16)	
Other	17 (11)	
Unspecified	4 (3)	

Table 2. Key studies on pain communication in sickle cell disease (SCD).

Author/Year	Title	Study Aim	Study Population	Main Findings
Qualitative Research				
Adegbola 2012	Voices of Adults Living With Sickle Cell Disease Pain	To describe the experiences of adults with SCD living with acute and chronic pain; to "advocate for the client's voice in SCD pain description and treatment approaches."	• Adults with SCD who reported having SCD pain for at least 2 years (n=13). Mean age 31 years (range 21-54). Recruited from national SCD support group.	• Adults with SCD felt "demoralized, stigmatized, and uncared for" by clinician disbelief, lack of knowledge of SCD, and lack of empathy, resulting in "non-therapeutic" patient-clinician relationships. • Participants found unidimensional pain scales reductive and insufficient. • Perceived clinician disrespect "increased emotional pain and compounded their physical pain." • Proposed "improved culturally appropriate approaches, provider presence, and intentional attentiveness."
Adelmann 2026	Patient Experiences of Acute Pain Communication in Sickle Cell Disease and Perspectives on Improving Clinician Communication	To "explore the complexity of patient-clinician pain communication," particularly how patient-clinician communication could be improved by future interventions.	• Adolescents and adults with SCD who had ≥1 lifetime hospitalization for SCD pain (n=30). Mean age 27.1 years (SD 8.7, range 16-52). Recruited from outpatient SCD clinic.	• Participants identified specific verbal and nonverbal cues they use to assess empathy and validation from clinicians. • Participants emphasized that clinician bedside manner must be paired with effective, knowledgeable pain management and accountability. • Proposed clinician skills intervention tailored for SCD context and integrating strategies for improving timely, high-quality pain management.
Alleyne 1994	The Management of Sickle Cell Crisis Pain as Experienced by Patients and Their Carers	To explore the perspectives of adults with SCD on hospitalization for pain management and nurses who have provided SCD pain care.	• Adults with SCD (n=10). No age data provided. Recruited from local SCD support group. • Nurses (n=10). Recruited from inpatient hematology ward.	• Participating individuals with SCD and nurses told similar stories of "poor practices" in SCD pain assessment and management. • Nurses interpreted patients' coping behavior (i.e., distraction strategies) as "not being compatible with genuine pain." • Individuals with SCD perceived that nurses had negative attitudes toward them, which exacerbated the pain experience.
Booker 2006	Pain Management in Sickle Cell Disease	To understand patient perspectives on clinicians' pain management decisions, with the goal of developing strategies for "minimizing inappropriate medication use and promoting a therapeutic unison."	• Adults with SCD who received care at SCD clinic and reported at least 1 VOE in past 12 months (n=10). Mean age 32 years (range 22-53). Recruited by mail from SCD clinic.	• SCD pain affects broad aspects of patients' lives. People who have not experienced the pain cannot understand it. • Participants felt mistrusted, stigmatized, and deprioritized by clinicians. They also perceived clinicians have little knowledge about SCD. They avoided seeking medical care when possible.
Brown 2015	Sickle Cell Disease Patients With and Without Extremely High Hospital Use: Pain, Opioids, and Coping	To characterize challenges experienced by patients with SCD and extremely high hospital use and compare their perspectives to those of patients	• Adults with SCD and extremely high hospital use (n=8; 100 hospital days/12 months) and matched adults with SCD with low hospital	• Individuals with EHHU described "reactive" and "defensive" behaviors toward clinicians and a "distrustful and dysfunctional" relationship, in contrast to individuals with low hospital use who presented as "self-aware" and collaborative.

		with SCD and low hospital use and clinicians.	use (n=8). Mean age 32.4 years (SD 8.7, range 23-54). Identified through electronic health record and approached in person or by telephone. • Clinicians identified by participants with extremely high hospital use as their "most important provider" (n=5; 4 hematologists and 1 non-physician).	
Campbell 2010	Coming of Age With Sickle Cell Disease and the Role of Patient as Teacher	The aim of this study was to explore the ways in which adolescents and young adults with SCD educate others and the meanings they give to their experiences.	• Adolescents and adults with SCD (n=17). Mean age 20 years (range 13-28). Recruited from SCD clinic.	• Adolescents and young adults with SCD are particularly underestimated in their expertise on their pain and disease. They attribute this to the invisibility of their pain and opioid-related stigma. • This can result in iatrogenic harm (e.g., administering a medication to which the patient has had a side effect, or providing a treatment that is harmful such as ice packs). Clinicians are perceived to have low SCD knowledge.
Childerhose 2024	"I Can't Cry on Cue": Exploring Distress Experiences of Persons With Sickle Cell	To explore sources of distress and strategies for managing distress among people with SCD.	• Adults with SCD who had been referred by hematologist to home visit program due to complex management. Mean age 42.8 years (SD 13.9). Recruited through home visit program.	• People with SCD experience distress related to pain itself, past experiences of clinician mistreatment, lack of control over pain management, waiting for treatment, and delays in seeking treatment. • People with SCD may "enact or withhold pain performance" as a strategy for managing the distress of seeking acute pain care. • Individuals with SCD place high value on honest, open communication and recommended that clinicians engage in dialogue about the pain management plan.
Ciribassi 2016	"We Don't Wear It on Our Sleeve": Sickle Cell Disease and the (In)Visible Body in Parts	To explore patient and clinician perspectives on "routine experiences with SCD, interpreting them through a lens of (in)visibility."	• Adults with SCD (n=95). Age data not provided. Recruited through SCD support group. • Clinicians (n=15; 4 physicians, 8 nurses, 3 social workers).	• Pain and patient expertise is de-legitimized due to its invisibility, in the context of racism and stigma. Patients may not adopt the "sick" behavior that clinicians are expecting. • Clinicians view people with SCD as "demanding" and "suspicious."
Coleman 2016	How Sickle Cell Disease Patients Experience, Understand and Explain Their Pain: An Interpretative	To explore "how adults with SCD experience acute and chronic pain, and how they make sense of their pain."	• Adults with SCD who experienced pain daily or most days (n=7). Mean age 40 years (range 24-57). Recruited from SCD support group.	• SCD pain is "unbearable, agonizing, continuous, inescapable and limitless." • People with SCD use analogies or personify their pain in an effort to verbalize a subjective experience.

	Phenomenological Analysis Study			
Collins 2022	Communicating And Understanding Pain: Limitations of Pain Scales for Patients With Sickle Cell Disorder and Other Painful Conditions	To explore perspectives of people with SCD to better understand "how we might improve communication and understanding of pain in clinical settings."	• Adolescents and adults with SCD (n=48; n=31 aged 13-18 years and n=17 aged 19-21 years). Recruited from SCD clinics and from communities via a network of patient advocates. *Same cohort as Miles et al., 2020.*	• Validation of numeric pain scales in controlled settings may not reflect the "social and contextual influences" on how patients with SCD express pain and clinicians interpret their expression. People with SCD may use numeric pain scales strategically based on their prior experiences with clinicians. • Participants noted lack of trust and compassion from clinicians • Suggested that clinicians assess pain more qualitatively rather than relying on pain scale.
Maxwell 1999	Experiences of Hospital Care and Treatment-Seeking Behavior for Pain From Sickle Cell Disease: Qualitative Study	To explore the experiences of people with SCD who had different frequencies of hospital admissions and identify nonclinical factors contributing to utilization patterns.	• Adolescents and adults with SCD, some of whom had ≥3 hospitalizations in the past 12 months and some who had 0-1 hospitalizations (n=57; 86% aged 20-40 years). Recruited from SCD clinic, clinician referral, prior research participation, media, and in-person during hospitalization.	• Participants described experiences of clinician mistrust, stigmatization, and undertreatment of pain. • Frequently-hospitalized participants described strategies for seeking care including developing relationships with clinicians, aggression ("so I held him, and I punched him"), passivity ("whatever they want to do, they can just do it to me") and use of multiple hospitals. • Proposed a model that clinicians' mistrust of patients with SCD leads them to exert excessive control over their pain management regimen, which undermines patients' self-reliance, self-knowledge, and capacity for self-management and leads to eroded trust and anxiety around care-seeking.
Miles 2020	Obstacles to Use of Patient Expertise to Improve Care: A Co-Produced Longitudinal Study of the Experiences of Young People With Sickle Cell Disease in Non-Specialist Hospital Settings	To explore the experiences of adolescents and young adults negotiating emergency care and unplanned hospitalizations, with a focus on how disease expertise is articulated by patients and received by clinicians.	• Adolescents and adults with SCD (n=48; n=31 aged 13-18 years and n=17 aged 19-21 years). Recruited from SCD clinics and from communities via a network of patient advocates. *Same cohort as Collins et al., 2022.*	• Participants described experiences of being ignored by staff with their expertise discounted. • "There is a tension between being encouraged to act as an expert in one's own condition whilst simultaneously having to navigate institutional and personal barriers to care when trying to voice that expertise. It is not enough to empower young people to assert their voice if the wider environment does not enable them to do so." • Proposed the need for communication skills trainings for adolescents transitioning to adult care.
Weisberg 2013	"I'm Talking About Pain": Sickle Cell Disease Patients With Extremely High Hospital Use	To explore the experiences of people with sickle cell disease and extremely high hospital use and generate hypotheses about its "antecedents and consequences."	• Adults with SCD and extremely high hospital use (n=8). Mean age 30 years (SD 4.9, range 24-37). Identified through electronic health record and	• Participants spoke about living with inescapable daily pain, social isolation, and "thwarted personal development in the setting of a long history of hospitalization and opioid use." • Clinicians were characterized as lacking in compassion and imposing pain plans without seeking patient input.

			approached during inpatient hospitalizations.	
Williams-Gray 2015	Challenges and Resilience in the Lives of Adults with Sickle Cell Disease	To explore current experiences of people with SCD in accessing health care services, and particularly experiences at a day hospital which was subsequently closed.	• Adults with SCD (n=23; range 18-70 years). Recruited through SCD community organization and snowball sampling.	• Participants described unkind, dehumanizing, and stigmatizing experiences with clinicians, long wait times, and experiences of racism. • Described the existential fear that accompanies SCD diagnosis. • Participants contrasted the usual acute care experiences with the positive experiences at the day hospital (infusion center).
Quantitative Research				
Brousseau 2009	Dissatisfaction With Hospital Care for Children With Sickle Cell Disease Not Due Only to Race and Chronic Disease	To compare parent-reported dissatisfaction with hospital care for children with SCD to parent-reported dissatisfaction with hospital care among children with asthma and children admitted to the general pediatric service.	• Parents of children and adolescents with SCD hospitalized with vaso-occlusive pain (n=34). Mean age of patients 11.1 years (SD 4.8, range 2-18). Recruited during inpatient hospitalization. • Routinely collected mailed surveys assessing hospital satisfaction for children with asthma (n=124) and children admitted to general pediatrics (n=481).	• Parents of children with SCD have greater dissatisfaction with care compared to parents of children with asthma and compared to parents of children admitted to the general pediatric service. • Nearly half of parents with SCD felt their children were treated differently on the basis of race, which was a higher proportion compared to parents of Black/African American children with asthma, another chronic disease.
Elander 2011	Respect, trust, and the management of sickle cell disease pain in hospital: comparative analysis of concern-raising behaviors, preliminary model, and agenda for international collaborative research to inform practice	To identify differences in the hospital experience of people with SCD in Baltimore versus London to better understand the impact of context on respect and trust.	• Adults with SCD in London (n=51; mean age 34 years, SD 10) and Baltimore (n=95; mean age 33 years, SD 10). Recruited through SCD clinic.	• Adults with SCD in Baltimore (versus London) reported more lifetime experiences of disputes with staff, of tampering with the analgesic delivery system, and of hospital self-discharge. Experiences of suspected/accused analgesic misuse were not significantly different. • Proposed a model in which "the key elements influencing concern-raising behaviors are under-treatment of pain, patients' experienced respect and trust, and patient-provider conflicts about pain and its management."
Haywood 2010	The Association of Provider Communication with Trust among Adults with Sickle Cell Disease	To examine the association of trust toward the medical profession among adults with sickle cell disease with patient ratings of the quality of their previous communication from providers.	• Adults with SCD (n=95). Mean age 32.9 years (SD 10.5). Recruited from SCD clinic, Emergency Department, inpatient hospitalization, or within 5 days of hospital discharge.	• Among adults with SCD, trust toward the medical profession was significantly associated with patient ratings of the quality of their previous communication from providers, after adjusting for patient clinical and demographic variables and potential attitudinal confounders (optimism and locus of control).

Haywood 2014	An unequal burden: Poor patient-provider communication and sickle cell disease	To compare the prevalence of patient-rated communication between adults with SCD versus a national sample of African American adults, to examine whether the poor communication patient-clinician communication in SCD is predominantly driven by race.	• African American adults with SCD (n=264; 75% aged 18-44 years). Recruited through SCD clinic.	• Compared to a national sample of African American patients, adults with SCD reported poorer communication across multiple domains: listening carefully to the patient, showing respect for what the patient had to say, and spending enough time with the patient. "Poor communication perceived by SCD patients was not reducible to their predominately African-American race." • Practices specifically tailored for SCD may be needed to improve communication in this population.
Kanter 2020	Perceptions of US Adolescents and Adults With Sickle Cell Disease on Their Quality of Care.	To identify patient-level barriers to seeking health care among people with SCD, with the goal of informing future interventions and implementation strategies to improve quality of care.	• Adolescents and adults with SCD (n=440). Mean age 27.8 years (SD 8.6). Recruited through SCD clinics at 8 participating sites, flyers, recruitment letters, health fairs, and websites.	• Care in the Emergency Department was characterized by perceived lack of empathy and poor SCD knowledge among clinicians, leading patients to postpone seeking acute care. Lack of perceived clinician empathy was associated with negative ratings of care quality. Interactions with longitudinal clinicians (i.e., hematologists) were rated highly.
Lattimer 2010	Problematic Hospital Experiences among Adult Patients with Sickle Cell Disease	To compare the experiences of hospitalized adults with SCD with a national sample of hospitalized patients.	• Adults with SCD (n=45). Mean age 31.2 years (range 20-59). Recruited in SCD clinic and during inpatient hospitalization.	• Compared to a national sample of hospitalized patients, individuals with SCD reported higher frequency of poor communication across several domains: doctors'/nurses' answers to questions were not clear; doctors/nurses did not always discuss patients' fears/anxieties; not easy to find someone to discuss concerns; had insufficient involvement in decisions about care/treatment; were not always treated with respect and dignity; staff gave conflicting information; staff did not do enough to control pain.
Theory, Commentary, and Reviews				
Bediako 2016	Interpersonal Contexts of Communication Between Sickle Cell Disease Patients and Providers	To advocate for examining patient-clinician interpersonal processes in SCD and the health-related outcomes associated with communication processes.	N/A	• The specific causes of poor patient-clinician communication in SCD, and the communication-related mechanisms that contribute to clinical outcomes, are not well known and should be studied.
Bloschichak 2026	A Scoping Review of Qualitative Studies on Inpatient Care for Individuals With Sickle Cell Disease	To synthesize qualitative literature on inpatient SCD experiences as a first step in defining inpatient quality of care for SCD.	N/A	• Most studies described negative inpatient experiences. • Patients and clinicians "struggled to align on pain treatment strategies." Clinicians made decisions based on generalizations and assumptions rather than individual patients' expertise and experiences. • Patients described trauma from repeated interactions with the healthcare system and experiences of racism and opioid-related stigma.

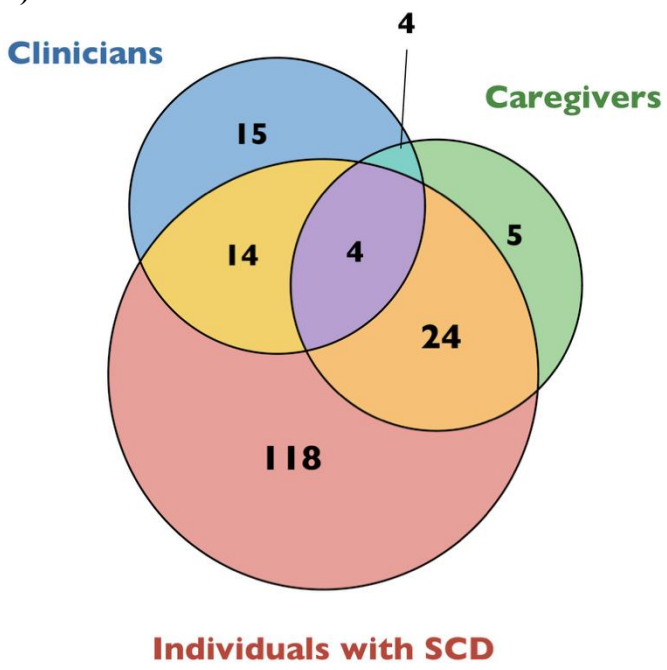
				• Strategies for successful inpatient care included clinician-patient shared decision-making and communication between inpatient and outpatient teams.
Schiavenato 2013	Pain Assessment During a Vaso-Occlusive Crisis in the Pediatric and Adolescent Patient: Rethinking Practice	To apply the Pain Assessment as a Social Transaction (PAST) to pediatric SCD pain care.	N/A	• Four features of pediatric SCD pain assessment are highlighted based on the PAST model: current pain assessment tools are limited; acute and chronic pain of varying etiologies co-exist; cognitive deficits are common; and sociocultural dynamics in the US exert influence over the pain assessment encounter.
Intervention Studies				
Haywood 2011	A Video-Intervention to Improve Clinician Attitudes Toward Patients With Sickle Cell Disease: The Results of a Randomized Experiment	To describe the results of a randomized controlled post-test-only experiment to test a video intervention designed to improve clinician attitudes toward adults with SCD.	• Internal medicine residents and inpatient nurses (n=276). Residents were recruited through a daily educational conference and nurses were recruited from a nursing retreat.	• Developed an 8-minute video depicting a hematologist speaking with three adults with SCD about the challenges that patients with SCD face when seeking pain treatment. • Inpatient clinicians randomized to the intervention group showed lower scores on the Negative Attitudes and Concern Raising Behaviors and higher scores on Positive Attitudes compared to the control group. There was no difference in scores of Red Flag Behaviors. • Concluded that a brief video intervention can improve clinician attitudes toward people with SCD.
Jean-Baptiste 2022	Individuals With Sickle Cell Disease Using SBAR as a Communication Tool: A Pilot Study	To pilot test an intervention aimed at improving the skills of patients with SCD at presenting useful clinical information to clinicians by teaching the Situation, Background, Assessment, Recommendation (SBAR) framework.	• Adults with SCD (n=15; range 18-62 years). Recruited from SCD clinic.	• Intervention included web-based training, video vignettes, and coaching to teach participants how to use the SBAR framework, then practiced these skills using a scripted video simulating a clinician in the Emergency Department. • Four of ten participants felt that the training exercise accurately depicted their experiences and was helpful. Six of ten felt that the overall training modules and communication tool was helpful. • Patients' use of SBAR may improve their credibility and assertiveness and thus improve their communication with clinicians.
Jenerette 2014	An intervention to decrease stigma in young adults with sickle cell disease.	To obtain preliminary data on the efficacy of a self-care management intervention aimed at lowering perceived health-related stigma for young adults with SCD by teaching assertive communication skills.	• Adolescents and adults with SCD (n=90). Mean age 25.8 years (SD 4.8, range 18-35). Recruited from SCD clinic.	• Based on the Theory of Self-Care Management which conceptualizes communication skills as a key resource improving SCD health outcomes. • Intervention involved two sessions delivered individually including the 8-minute video tested in Haywood et al., 2011, education on the importance of seeking care for vaso-occlusive episodes, and videos teaching assertive communication skills. Control

				condition involved participation in two life-review interviews. • Participants in the intervention group reported higher levels of perceived health-related stigma compared to the control group.
Mulchan 2024	Initial Evaluation of an Intervention to Address Provider Implicit Bias in Pediatric Sickle Cell Disease Pain Care: A Mixed Methods Pilot Study	To explore the feasibility, acceptability, and preliminary impact of an intervention aimed at decreasing implicit bias and improving the effectiveness of pain treatment and clinical decision-making in pediatric sickle cell clinicians.	• Physicians, advanced practice providers, and nurses who provide care to youth with SCD in the inpatient or outpatient setting (n=36). Recruited though team huddles, email, and flyers.	• Intervention involved a clinician skills training on individuation and perspective-taking. Control involved a pre-recorded virtual training on pediatric SCD pain management. Clinicians were randomized to the intervention vs control group, then evaluated with virtual patient vignettes. • Clinicians demonstrated pro-White implicit bias. The intervention did not significantly affect implicit bias. Clinicians selected appropriate pain treatment plans in virtual patient vignettes, with treatment choices unrelated to implicit bias.
Thomas 2006	Communication Skills and Cultural Awareness Courses for Healthcare Professionals Who Care for Patients With Sickle Cell Disease	To evaluate the impact of a pilot communication skills and cultural awareness course for clinicians who provide care for people with SCD.	• Physicians, nurses, midwives, psychologists, pharmacist, and physiotherapist who provide care for individuals with SCD in the inpatient and Emergency Department setting (n=47).	• Intervention was a clinician skills training involving videos, role-play, and group exercises. • Clinicians' confidence in "dealing with challenging situations" increased from pre- to post-course and were maintained through 6-month follow up.
Instrument Development/Validation				
Elander 2019	Development and Validation of The Satisfaction with Treatment for Pain Questionnaire (STPQ) Among Patients with Sickle Cell Disease	"To produce a valid and reliable measure of satisfaction with treatment for pain that was designed specifically to evaluate hospital treatment of painful sickling episodes among adolescent and adult SCD patients."	• Adolescents and adults with SCD. Focus groups (n=28): 10 adolescents (aged 14-19 years) and 18 adults (aged ≥20 years). Validation (n=120): mean age 24.4 years (SD 10.0). Recruited through SCD clinic and SCD organization.	• Developed 18-item measure with five subscales: Communication and Involvement, Respect and Dignity, Pain Control, Staff Attitudes and Behavior, and Overall Satisfaction. • Developed based on focus groups with adolescents and adults with SCD and demonstrated high internal reliability and convergent validity. • STPQ is a "convenient brief measure that can be used to inform and evaluate improvements in healthcare for adolescent and adult patients with SCD."
Evensen 2016	Quality of care in sickle cell disease: Cross-sectional study and development of a measure for adults reporting on ambulatory and emergency department care	To develop a patient-reported outcome measure to assess the quality of ambulatory and Emergency Department care for adults with SCD.	• Adolescents and adults with SCD (n=556; 63% aged 18-34 years). Recruited through SCD clinics and community organizations at 7 participating centers.	• Developed 27-item measure with three subscales: Provider Interaction, Access, and ED Care. • Modeled after the Consumer Assessments of Healthcare Providers and Systems (CAHPS) surveys and developed based on literature review, working groups, focus groups, and individual interviews. Showed high reliability and validity. • "The needed improvement of adult health care for SCD is literally a matter of life and death" due to treatment

				delays in the Emergency Department and avoidance of care seeking by patients.
O'Brien 2025	The use of abstract animations and a graphical body image for assessing pain outcomes among adults with sickle cell disease.	To demonstrate preliminary construct validity in SCD of Painimations (pain animations), a digital tool using abstract animations to capture respondents' pain experiences.	• Adults with SCD who had chronic pain (≥4 days per week for 3 months and/or prescribed daily opioids; n=359). Mean age 36 years (SD 10). Recruited in person at SCD clinics (7 sites) and online (through 25 community-based organizations).	• This study validates Painimation for the SCD population, providing a nonverbal assessment tool that may facilitate communication with clinicians and reduce literacy barriers.

Figure 2. Participant characteristics. Overlapping circles indicated studies that enrolled more than one participant type. A) Venn diagram showing number of studies enrolling individuals with sickle cell disease, caregivers, and clinicians as participants (total n=184). B) Venn diagram showing number of studies enrolling children (age 0-17 years), adolescents and young adults (age 10-24 years), and adults with sickle cell disease (age ≥18 years) as participants (total n=160).

A)



B)

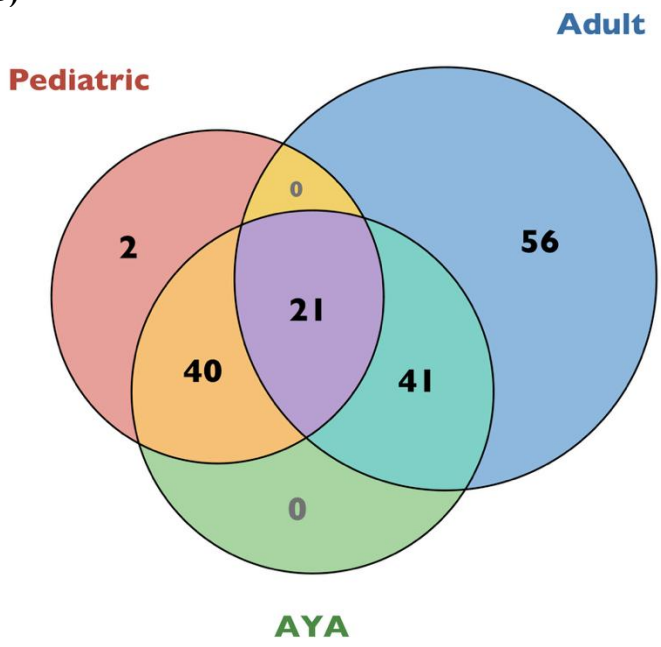
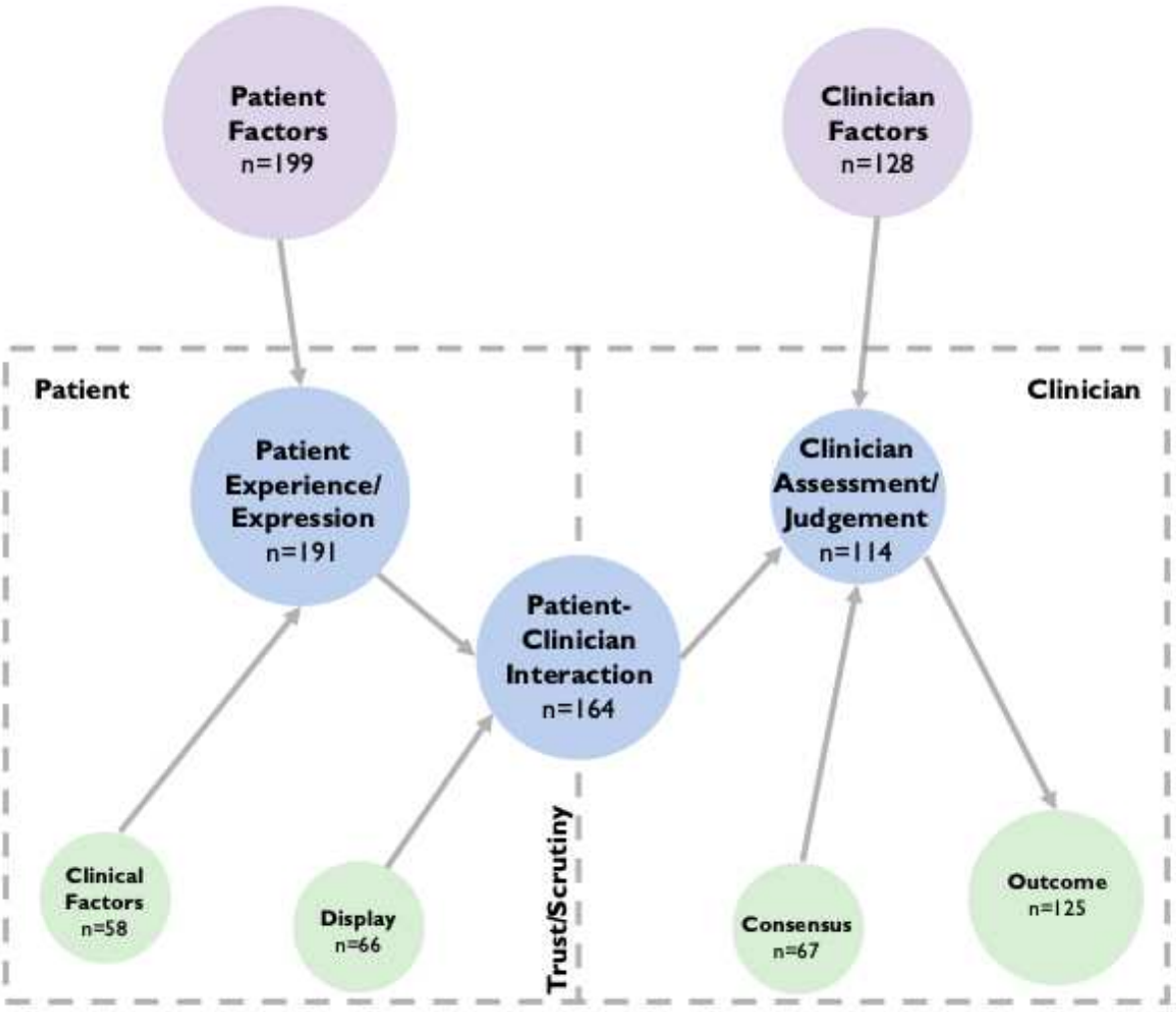


Figure 3. Included studies mapped onto the Pain Assessment as a Social Transaction (PAST) model for pain communication. The size of each bubble is proportional to the number of articles relevant to the indicated model component (studies could reference multiple components). *Patient Factors:* factors and experiences that shape the patient's pain communication behavior. *Clinician Factors:* factors and experiences that shape the clinician's pain communication behavior. *Patient Experience/Expression:* the patient's internal, subjective experience of pain and verbal/nonverbal expression of pain. *Patient-Clinician Interaction:* the interface between the patient and clinician, including trust or scrutiny between them. *Clinician Assessment/Judgement and Intervention:* the clinician's process of assessing the pain and forming a judgement about it, followed by the clinician's intervention on the pain. *Clinical Factors* that impact the communication interaction include age/developmental status, cognitive abilities, and medication effects. *Display*: the degree to which a patient suppresses or externally demonstrates their pain. *Consensus:* the degree to which patient and clinician agree on the pain formulation. *Outcome:* degree to which the clinician's intervention effectively treats the patient's pain.



Supplemental Material 1. PRISMA-ScR checklist.

SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE #
TITLE			
Title	1	Identify the report as a scoping review.	1
ABSTRACT			
Structured summary	2	Provide a structured summary that includes (as applicable): background, objectives, eligibility criteria, sources of evidence, charting methods, results, and conclusions that relate to the review questions and objectives.	2
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of what is already known. Explain why the review questions/objectives lend themselves to a scoping review approach.	4
Objectives	4	Provide an explicit statement of the questions and objectives being addressed with reference to their key elements (e.g., population or participants, concepts, and context) or other relevant key elements used to conceptualize the review questions and/or objectives.	4
METHODS			
Protocol and registration	5	Indicate whether a review protocol exists; state if and where it can be accessed (e.g., a Web address); and if available, provide registration information, including the registration number.	5
Eligibility criteria	6	Specify characteristics of the sources of evidence used as eligibility criteria (e.g., years considered, language, and publication status) and provide a rationale.	5; Supplemental Material 2
Information sources*	7	Describe all information sources in the search (e.g., databases with dates of coverage and contact with authors to identify additional sources), as well as the date the most recent search was executed.	6
Search	8	Present the full electronic search strategy for at least 1 database, including any limits used, such that it could be repeated.	Supplemental Material 3
Selection of sources of evidence†	9	State the process for selecting sources of evidence (i.e., screening and eligibility) included in the scoping review.	6
Data charting process‡	10	Describe the methods of charting data from the included sources of evidence (e.g., calibrated forms or forms that have been tested by the team before their use, and whether data charting was done independently or in duplicate) and any processes for obtaining and confirming data from investigators.	7
Data items	11	List and define all variables for which data were sought and any assumptions and simplifications made.	Supplemental Material 4
Critical appraisal of individual sources of evidence§	12	If done, provide a rationale for conducting a critical appraisal of included sources of evidence; describe the methods used and how this information was used in any data synthesis (if appropriate).	N/A
Synthesis of results	13	Describe the methods of handling and summarizing the data that were charted.	7
RESULTS			

SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE #
Selection of sources of evidence	14	Give numbers of sources of evidence screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally using a flow diagram.	8; Figure 1
Characteristics of sources of evidence	15	For each source of evidence, present characteristics for which data were charted and provide the citations.	Table 1, Table 2, Supplemental Material 6
Critical appraisal within sources of evidence	16	If done, present data on critical appraisal of included sources of evidence (see item 12).	N/A
Results of individual sources of evidence	17	For each included source of evidence, present the relevant data that were charted that relate to the review questions and objectives.	Table 1, Table 2, Supplemental Material 6
Synthesis of results	18	Summarize and/or present the charting results as they relate to the review questions and objectives.	9-28
DISCUSSION			
Summary of evidence	19	Summarize the main results (including an overview of concepts, themes, and types of evidence available), link to the review questions and objectives, and consider the relevance to key groups.	29
Limitations	20	Discuss the limitations of the scoping review process.	33-34
Conclusions	21	Provide a general interpretation of the results with respect to the review questions and objectives, as well as potential implications and/or next steps.	34
FUNDING			
Funding	22	Describe sources of funding for the included sources of evidence, as well as sources of funding for the scoping review. Describe the role of the funders of the scoping review.	1

Supplemental Material 2. Population, Concept, Context (PCC) for included studies and inclusion and exclusion criteria.

Category	Include	Exclude
Population	• Focuses on people with SCD (any genotype, any age) • Study may include multiple disease groups, but SCD should be a main focus • May be studies of caregiver communication about pain	• Only sickle cell trait is discussed • Animal model (no human subjects)
Concept	• Provides insight into how people with SCD communicate about SCD-related pain • Verbal or nonverbal communication • Acute or chronic pain • Not limited to vaso-occlusive pain; procedural or surgical pain may be included	• Describes measurement of pain or development of a pain scale *without* discussing communication between patients, caregivers, or clinicians
Context	• Inpatient, outpatient, or Emergency Department • Community-based or home-based (non-medical setting) • Any country	
Format	• Any study design, including review articles • Letters, commentaries, short reports may be included	• Abstracts with no full article • Conference proceedings • Books • Non-peer reviewed publications (e.g., dissertations)
Language	• Both abstract and full text are in English	• Abstract and/or full text are in a language other than English

Supplemental Material 3. Complete search strategy.

("Anemia, Sickle Cell"[Mesh] OR sickle-cell[tiab] OR sickling[tiab] OR hemoglobin-s[tiab] OR Hbs-disease*[tiab] OR SCD[tiab])

AND (("Pain Measurement"[Majr] OR "Pain/Ethnology"[mesh] OR "Pain/classification"[Mesh] OR "Pain/psychology"[Mesh] OR "Pain/Nursing"[Mesh] OR faces-scale*[tiab] OR "baker wong"[tiab:~2] OR analgesi*-test*[tiab] OR nocicept*-test*[tiab] OR formalin-test*[tiab] OR pain-measurement[tiab] OR pain-assessment*[tiab] OR assess*-pain[tiab] OR pain-scale*[tiab] OR pain-rating*[tiab] OR measure*-pain*[tiab] OR rate*-pain*[tiab])

OR (("Communication"[Majr] OR Ethnology[mesh] OR communicat*[tiab] OR miscommunicat*[tiab] OR language*[tiab] OR spoken[tiab] OR speak*[tiab] OR nonverbal[tiab] OR verbal*[tiab] OR crying[tiab] OR cry[tiab] OR cries[tiab] OR cried[tiab] OR face[tiab] OR facial*[tiab] OR speech[tiab] OR voice*[tiab] OR gestur*[tiab] OR haptic*[tiab] OR smile*[tiab] OR smiling[tiab] OR laugh*[tiab] OR grimac*[tiab] OR express*[tiab] OR flinch*[tiab] OR blink*[tiab] OR nonspeech*[tiab] OR gesticulat*[tiab] OR describ*[tiab] OR descript*[tiab] OR classif*[tiab] OR distinguish*[tiab])

AND ("Pain"[Majr] OR ache[tiab] OR aches[tiab] OR aching[tiab] OR arthralgia[tiab] OR headache*[tiab] OR neuralgi*[tiab] OR pain[tiab] OR pains[tiab] OR painful*[tiab])))

Supplemental Material 4. Data extraction form.

1. First author
2. Year of publication
3. Journal
4. Lead author contact details
5. Country in which the study was conducted
6. Aim of study
7. Statement of problem (if relevant to pain communication)
8. Study design
9. Parent study
10. Study start/end date
11. Study funding sources
12. Disclosed conflicts of interest for study authors
13. Population description
14. Age range (as described in study): pediatric, AYA, adult, other
15. Population type (as described in study): people with SCD, caregivers/family members, clinicians, other
16. Pain type: acute/vaso-occlusive, chronic, neuropathic, procedural/surgical, leg ulcers, priapism, other
17. Study setting: inpatient hospital, Emergency Department, clinic, community, home, other
18. Inclusion criteria
19. Exclusion criteria
20. Method of participant recruitment: phone, mail, clinic, SCD groups, other
21. Recruitment outcomes
22. Total number of participants
23. Participant demographics: gender/sex, age, race/ethnicity, genotype, disease severity, socioeconomic status (e.g., income, neighborhood, insurance), employment, education, relationship status, other demographics
24. Measures of pain: NRS, VAS, Structured Pain Interview, SCPBI/SCPBI-Y, McGill Pain Questionnaire, PAINReportIt, APPT, PedsQL, Body diagram, Diary, other
25. Measures of communication: ASCQ-Me Quality of Care, Patient's Self-Competence Scale, other
26. Theoretical model
27. Intervention or exposure
28. Which review questions are addressed by this paper?
    a. What is known about how people with SCD communicate about pain?
    b. What is the role of caregivers in communicating about pain for people with SCD?
    c. What methods have been used to assess SCD-related pain in clinical settings, and which have been most effective?

    d. How does pain communication for people with SCD develop over time, from childhood into adulthood ?
    e. What interventions have been tested to improve pain communication for people with SCD?
29. Pain communication model: patient factors, clinician factors, patient experience, patient-clinician, clinician response, clinical factors, display, consensus, outcome
30. What secondary topics are included in this paper? description, measurement, management, coping, patient-clinician, patient/caregiver, bias/stigma, self-management, other
31. Experimental/Observational outcomes
32. Qualitative outcomes
33. Other Study Designs key results
34. Discussion: Key points about pain communication
35. Study limitations
36. Biased language
37. Suggested future directions
38. Miscellaneous notes

Supplemental Material 5. Methods for categorizing age range for studies including individuals with sickle cell disease as participants (n=160).

Each study was assigned to one or more non-exclusive age categories: pediatric (0-17 years), adolescent/young adult (AYA, 10-24 years), adult (≥18 years). AYA age range was selected based on the World Health Organization definition.

For studies that reported descriptive age statistics (n=143), a study was considered to qualify for an age category if an estimated 20% of its sample fell within the group's age range. For studies that did not report descriptive age statistics (n=17), the age group designations were determined based on the narrative description of the study population.

The proportion of each study sample falling within each age group (pediatric, AYA, and adult) was estimated according to the following process. Analyses were performed using Microsoft Excel.

1. If the exact ages of participants were reported (n=3), the proportion of participants in each age group were calculated directly.
2. If mean and standard deviation were reported (n=67), the proportion was estimated using a normal approximation to the underlying age distribution, bounded by the study's reported maximum/minimum age where available.
3. If the age range was reported (no standard deviation; n=43), the age-group proportions were estimated assuming that ages were uniformly distributed across that range.
4. If the age-bin frequencies (n=21) were reported, the age-group proportions were estimated assuming that ages were uniformly distributed within bins.
5. If age statistics for multiple subgroups were reported (n=9), the age group proportions were estimated for each subgroup using the methods above and combined, weighted by sample size.

Supplemental Material 6. Complete list of included studies.

Author/Year	Title	Country	Study Design	Additional Study Characteristics	Participants Enrolled
Abadesso 2020	Pain in Children and Adolescents With Sickle Cell Disease: Multidimensional Assessment	Portugal	Cross-sectional		Individuals with SCD; Caregivers
Abdallah 2020	Emergency Department Utilization for Patients Living With Sickle Cell Disease: Psychosocial Predictors of Health Care Behaviors	United States	Cross-sectional		Individuals with SCD
Abu Al Hamayel 2021	Pain Experiences of Adults With Sickle Cell Disease and Hematopoietic Stem Cell Transplantation: A Qualitative Study	United States	Qualitative research		Individuals with SCD
Abudawood 2022	Novel Measure of Pain Location in Adults With Sickle Cell Disease	United States	Prospective descriptive	Secondary Analysis; Instrument Development/ Validation	Individuals with SCD
Addis 2007	The Physical, Social and Psychological Impact of Priapism on Adult Males With Sickle Cell Disorder	United Kingdom	Qualitative research		Individuals with SCD
Adegbola 2011	Using Lived Experiences of Adults to Understand Chronic Pain: Sickle Cell Disease, an Exemplar	United States	Expert Opinion or Commentary		
Adegbola 2012	Voices of Adults Living With Sickle Cell Disease Pain	United States	Qualitative research		Individuals with SCD
Adelmann 2026	Patient Experiences of Acute Pain Communication in Sickle Cell Disease and Perspectives on Improving Clinician Communication	United States	Qualitative research		Individuals with SCD
Ahlawat 2026	Living With Pain and Hope: A Phenomenological Exploration of Adolescents Experiences of With Sickle Cell Disease in Central India	India	Qualitative research		Individuals with SCD
Aisiku 2007	Patient Satisfaction in Specialized Versus Nonspecialized Adult Sickle Cell Care Centers: The PiSCES Study	United States	Cross-sectional	Secondary Analysis	Individuals with SCD
Ajayi 2016	Palliative Care Teams as Advocates for Adults With Sickle Cell Disease	United States	Expert Opinion or Commentary		
Al Sayigh 2023	Health-Related Quality of Life and Service Barriers Among Adults With Sickle Cell Disease in Saudi Arabia	Saudi Arabia	Cross-sectional		Individuals with SCD

Alberts 2024	Agreement Between Youth and Caregiver Report of Pain and Functioning in Pediatric Sickle Cell Disease: PedsQL Sickle Cell Disease Module	Canada	Cross-sectional	Secondary Analysis	Individuals with SCD
Alleyne 1994	The Management of Sickle Cell Crisis Pain as Experienced by Patients and Their Carers	United Kingdom	Qualitative research		Individuals with SCD; Clinicians
Alqahtani 2025	Saudi in Vaso-Occlusive Crisis Accessing Healthcare for Pain Management: A Qualitative Study	Saudi Arabia	Qualitative research		Individuals with SCD
Alyami 2026	Palliative Care Needs of Adults Severely Affected by Sickle Cell Disease: A Mixed-Methods Systematic Review	Multiple (Saudi Arabia, UK, US)	Systematic/ Scoping Review	Mixed Methods	
Alzayer 2026	Lived Experiences of Patients With Sickle Cell Disease and Kidney Failure: Insights From a Qualitative Study	Saudi Arabia	Qualitative research		Individuals with SCD
Anim 2019	Living Fully With Sickle Cell Disease	United States	Expert Opinion or Commentary		
Armstrong 1992	Impact of Children's Sickle Cell History on Nurse and Physician Ratings of Pain and Medication Decisions	United States	Randomized experiment		Clinicians
Atoui 2015	The Daily Experiences of Adolescents in Lebanon With Sickle Cell Disease	Lebanon	Qualitative research		Individuals with SCD
Bakshi 2017	Novel Metrics in the Longitudinal Evaluation of Pain Data in Sickle Cell Disease	United States	Prospective descriptive	Instrument Development/ Validation; Longitudinal	Individuals with SCD
Ballas 1993	Pain Measurement in Hospitalized Adults With Sickle Cell Painful Episodes	United States	Pre-Post Measurement Study		Individuals with SCD
Ballas 2020	How I Treat Acute and Persistent Sickle Cell Pain.	United States	Case series		
Bargain 2021	Self-Management of Pain Crisis in Patients With Sickle Cell Disease	France	Qualitative research		Individuals with SCD
Bediako 2016	Interpersonal Contexts of Communication Between Sickle Cell Disease Patients and Providers	United States	Expert Opinion or Commentary		
Bergman 2013	Sickle Cell Disease and the "Difficult Patient" Conundrum	United States	Expert Opinion or Commentary		
Bernardo 2026	Disbelieved and Dismissed: Racial Inequities in Sickle Cell Pain Management	Brazil	Expert Opinion or Commentary		

Beyer 1999	A Chronology of Pain and Comfort in Children With Sickle Cell Disease	United States	Prospective descriptive	Longitudinal; Mixed Methods	Individuals with SCD; Caregivers
Beyer 1999	Practice Guidelines for the Assessment of Children With Sickle Cell Pain	United States	Clinical Practice Guideline		
Blake 2020	Level of Agreement Between Adolescents' Self-Assessment and Parent Proxy Report of Health-Related Quality of Life in Adolescents With Sickle Cell Disease	Jamaica	Cross-sectional		Individuals with SCD
Blakey 2023	Effects of Experienced Discrimination in Pediatric Sickle Cell Disease: Caregiver and Provider Perspectives	United States	Cross-sectional	Mixed Methods	Caregivers; Clinicians
Bloschichak 2026	A Scoping Review of Qualitative Studies on Inpatient Care for Individuals With Sickle Cell Disease	United States	Systematic/ Scoping Review		
Booker 2006	Pain Management in Sickle Cell Disease	United Kingdom	Qualitative research		Individuals with SCD
Brousseau 2009	Dissatisfaction With Hospital Care for Children With Sickle Cell Disease Not Due Only to Race and Chronic Disease	United States	Cross-sectional		Individuals with SCD
Brown 2015	Sickle Cell Disease Patients With and Without Extremely High Hospital Use: Pain, Opioids, and Coping	United States	Qualitative research		Individuals with SCD; Clinicians
Brown 2016	Family Caregiving for Adults With Sickle Cell Disease and Extremely High Hospital Use	United States	Qualitative research		Individuals with SCD; Caregivers
Brown 2024	The Misuse of Malingering Diagnoses in Individuals With Sickle Cell Disease	United States	Expert Opinion or Commentary		
Bulgin 2018	Stigma of Sickle Cell Disease: A Systematic Review	United States	Systematic/ Scoping Review		
Butler 1993	Functions of an Adult Sickle Cell Group: Education, Task Orientation, and Support	United States	Program description		
Campbell 2010	Coming of Age With Sickle Cell Disease and the Role of Patient as Teacher	United States	Qualitative research		Individuals with SCD
Campelo 2018	The Pain of Children With Sickle Cell Disease: The Nursing Approach	Brazil	Qualitative research		Clinicians
Carlson 2022	Family-Centered Communication in Pediatric Sickle Cell Disease	United States	Qualitative research		Individuals with SCD; Caregivers
Carvalho 2021	Why Does Your Pain Never Get Better? Stigma and Coping Mechanism in People With Sickle Cell Disease	Brazil	Qualitative research		Individuals with SCD

Chakravorty 2018	Patient-Reported Experience Measure in Sickle Cell Disease	United Kingdom	Cross-sectional	Instrument Development/ Validation; Mixed Methods	Individuals with SCD; Caregivers
Childerhose 2023	Treating Chronic Pain in Sickle Cell Disease - The Need for a Biopsychosocial Model	United States	Expert Opinion or Commentary		
Childerhose 2024	"I Can't Cry on Cue": Exploring Distress Experiences of Persons With Sickle Cell	United States	Qualitative research		Individuals with SCD
Ciribassi 2016	"We Don't Wear It on Our Sleeve": Sickle Cell Disease and the (In)Visible Body in Parts	United States	Qualitative research		Individuals with SCD; Clinicians
Coleman 2016	How Sickle Cell Disease Patients Experience, Understand and Explain Their Pain: An Interpretative Phenomenological Analysis Study	United Kingdom	Qualitative research		Individuals with SCD
Collins 2022	Communicating and Understanding Pain: Limitations of Pain Scales for Patients With Sickle Cell Disorder and Other Painful Conditions	United Kingdom	Qualitative research		Individuals with SCD
Conner-Warren 1996	Pain Intensity and Home Pain Management of Children With Sickle Cell Disease	United States	Prospective descriptive		Individuals with SCD
Connolly 2023	Clinical Considerations for Behavioral Pain Management in Co-Occurring Acute and Chronic Pain Presentations	United States	Expert Opinion or Commentary		
Cox 2017	Family Engagement in Pediatric Sickle Cell Disease Visits	United States	Cross-sectional		Individuals with SCD; Clinicians
Coyne 2022	Validation of Patient-Reported Vaso-Occlusive Crisis Day as an Endpoint in Sickle Cell Disease Studies	United States	Prospective cohort	Instrument Development/ Validation; Longitudinal; Mixed Methods	Individuals with SCD; Caregivers
Crandall 2005	Multidimensional Assessment Using the Adolescent Pediatric Pain Tool: A Case Report	United States	Case report		
Crego 2021	Patient Perspectives of Sickle Cell Management in the Emergency Department	United States	Cross-sectional	Mixed Methods	Individuals with SCD
Crusto 2024	Perceptions of Care and Perceived Discrimination: A Qualitative Assessment of Adults Living With Sickle Cell Disease	United States	Qualitative research		Individuals with SCD
Dampier 2002	Characteristics of Pain Managed at Home in Children and Adolescents With Sickle Cell Disease by Using Diary Self-Reports	United States	Prospective descriptive	Instrument Development/ Validation	Individuals with SCD

Darbari 2017	Pain-Measurement Tools in Sickle Cell Disease: Where Are We Now?	United States	Narrative Review		
Day 2020	Vaso-Occlusive Pain and Menstruation in Sickle Cell Disease: A Focus Group Analysis	United States	Qualitative research		Individuals with SCD
del Pino-Jones 2019	Improving Care for Patients With Sickle Cell Disease: A Qualitative Study of Hospitalized Sickle Cell Patients	United States	Qualitative research		Individuals with SCD
Delgado 2025	Are Patients With Sickle Cell Disease Still Being Failed by the Healthcare System?	United Kingdom	Expert Opinion or Commentary		
Derlega 2014	How Patients' Self-Disclosure About Sickle Cell Pain Episodes to Significant Others Relates to Living With Sickle Cell Disease	United States	Cross-sectional		Individuals with SCD
Dobson 2014	Using Guided Imagery to Manage Pain in Young Children With Sickle Cell Disease	United States	Non-Randomized Experimental study		Individuals with SCD
Drahos 2025	Qualitative Assessment of Health-Related Quality of Life Impacts Associated With Sickle Cell Disease in the United States and United Kingdom	Multiple (UK, US)	Qualitative research		Individuals with SCD; Caregivers
Durgam 2023	Patient and Caregiver Perspectives on Care-Seeking During a Vaso-Occlusive Crisis in Sickle Cell Disease: Results From Qualitative Interviews in Canada	Canada	Qualitative research		Individuals with SCD; Caregivers
Dyal 2021	Reflections of Healthcare Experiences of African Americans With Sickle Cell Disease or Cancer: A Qualitative Study	United States	Qualitative research		Individuals with SCD
Edwards 2026	Implicit Bias in Pain Management: The Intersection of Stigma, Race, and Chronic Disease in Sickle Cell Disease	United States	Narrative Review		
Elander 1996	A Review of Evidence About Factors Affecting Quality of Pain Management in Sickle Cell Disease	United Kingdom	Systematic/ Scoping Review		
Elander 2004	Understanding the Causes of Problematic Pain Management in Sickle Cell Disease: Evidence That Pseudoaddiction Plays a More Important Role Than Genuine Analgesic Dependence	United Kingdom	Qualitative research		Individuals with SCD

Elander 2011	Respect, Trust, and the Management of Sickle Cell Disease Pain in Hospital: Comparative Analysis of Concern-Raising Behaviors, Preliminary Model, and Agenda for International Collaborative Research to Inform Practice	Multiple (UK, US)	Cross-sectional		Individuals with SCD
Elander 2019	Development and Validation of the Satisfaction With Treatment for Pain Questionnaire (STPQ) Among Patients With Sickle Cell Disease	United Kingdom	Cross-sectional	Instrument Development/ Validation; Mixed Methods	Individuals with SCD
Ely 2002	Caregiver Report of Pain in Infants and Toddlers With Sickle Cell Disease: Reliability and Validity of a Daily Diary	United States	Prospective descriptive	Instrument Development/ Validation; Longitudinal	Individuals with SCD; Caregivers
Evensen 2016	Quality of Care in Sickle Cell Disease: Cross-Sectional Study and Development of a Measure for Adults Reporting on Ambulatory and Emergency Department Care	United States	Cross-sectional	Instrument Development/ Validation	Individuals with SCD
Ezenwa 2016	Healthcare Injustice in Patients With Sickle Cell Disease	United States	Qualitative research		Individuals with SCD
Ezenwa 2016	Satisfied or Not Satisfied: Pain Experiences of Patients With Sickle Cell Disease	United States	Cross-sectional	Baseline Data of Clinical Trial	Individuals with SCD
Faremi 2023	Clients' Satisfaction With Pain Management by Healthcare Providers During Sickle Cell Crisis in Selected Health Facilities in Ogun State Nigeria - A Cross Sectional Study	Nigeria	Cross-sectional		Individuals with SCD
Fearon 2019	Pediatric Residents' Perceived Barriers to Opioid Use in Sickle Cell Disease Pain Management	United States	Cross-sectional	Mixed Methods	Clinicians
Fosdal 2015	Perception of Pain Among Pediatric Patients With Sickle Cell Pain Crisis	United States	Prospective descriptive		Individuals with SCD
Franck 2002	Assessment of Sickle Cell Pain in Children and Young Adults Using the Adolescent Pediatric Pain Tool	United States	Cross-sectional		Individuals with SCD
Frost 2016	Improving Sickle Cell Transitions of Care Through Health Information Technology	United States	Qualitative research	Instrument Development/ Validation	Individuals with SCD; Caregivers; Clinicians
Fuggle 1996	Pain, Quality of Life, and Coping in Sickle Cell Disease	United Kingdom	Case-Control		Individuals with SCD
Gil 1989	Coping With Sickle Cell Disease Pain	United States	Narrative Review		
Gil 1990	Pain Drawings and Sickle Cell Disease Pain	United States	Cross-sectional		Individuals with SCD

Gil 1994	Behavioral Assessment of Sickle Cell Disease Pain	United States	Narrative Review		
Gil 1994	Observation of Pain Behaviors During Episodes of Sickle Cell Disease Pain	United States	Cross-sectional	Instrument Development/ Validation	Individuals with SCD
Glassberg 2013	Among Emergency Physicians, Use of the Term "Sickler" Is Associated With Negative Attitudes Toward People With Sickle Cell Disease	United States	Cross-sectional		Clinicians
Glassberg 2017	Improving Emergency Department-Based Care of Sickle Cell Pain	United States	Expert Opinion or Commentary		
Gorman 1999	Sickle Cell Disease: Do You Doubt Your Patient's Pain?	United States	Educational or Instructional		
Graff 2012	Exploring Family Communication About Sickle Cell Disease in Adolescence	United States	Qualitative research		Individuals with SCD; Caregivers
Granados 2009	Pain Experience in Hospitalized Adults With Sickle Cell Disease	United States	Prospective descriptive		Individuals with SCD
Graumlich 2001	Multidimensional Assessment of Pain in Pediatric Sickle Cell Disease	United States	Cross-sectional		Individuals with SCD; Caregivers
Grismore 2025	Barriers to Care for Adults With Sickle Cell Disease: A Qualitative Descriptive Study	United States	Qualitative research		Individuals with SCD; Caregivers; Clinicians
Guarino 2024	Attitudes and Beliefs Regarding Pain and Discrimination Among Black Adults With Sickle Cell Disease: A Mixed Methods Evaluation of an Adapted Chronic Pain Intervention.	United States	Cross-sectional	Mixed Methods	Individuals with SCD
Gupta 2016	Cognitive Testing of an Electronic Version of the Faces Pain Scale-Revised With Pediatric and Adolescent Sickle Cell Patients	United States	Qualitative research	Instrument Development/ Validation	Individuals with SCD; Caregivers
Haridasa 2019	Student Perspectives on Managing Sickle Cell Disease at School	United States	Qualitative research		Individuals with SCD
Haynes 2020	Management of Paediatric Sickle Cell Disease Pain in Emergency Departments in N.Z.	New Zealand	Expert Opinion or Commentary		
Haywood 2010	Hospital Self-Discharge Among Adults With Sickle-Cell Disease (SCD): Associations With Trust and Interpersonal Experiences With Care	United States	Cross-sectional		Individuals with SCD
Haywood 2010	The Association of Provider Communication With Trust Among Adults With Sickle Cell Disease	United States	Cross-sectional		Individuals with SCD
Haywood 2011	A Video-Intervention to Improve Clinician Attitudes Toward Patients With Sickle Cell Disease: The Results of a Randomized Experiment	United States	Randomized experiment		Clinicians

Haywood 2013	Disrespectful Care in the Treatment of Sickle Cell Disease Requires More Than Ethics Consultation	United States	Expert Opinion or Commentary		
Haywood 2014	An Unequal Burden: Poor Patient-Provider Communication and Sickle Cell Disease	United States	Cross-sectional		Individuals with SCD
Haywood 2015	Improving Clinician Attitudes of Respect and Trust for Persons With Sickle Cell Disease	United States	Non-Randomized Experimental study		Clinicians
Ibemere 2025	Impact of Individualized Versus Weight-Based Pain Protocols on Patient Satisfaction for Patients With Sickle Cell Disease Experiencing a Vaso-Occlusive Episode	United States	Randomized controlled trial		Individuals with SCD
Ibitoye 2025	You Only Work With What You Know: Healthcare Providers' Experiences Using Non-Pharmacological Interventions in Managing Sickle Cell Crisis Pain in Adolescents.	Nigeria	Qualitative research		Clinicians
Ibitoye 2026	Non-Pharmacological Interventions for Managing Sickle Cell Crisis Pain: A Qualitative Study on Adolescents' and Caregivers' Experiences	Nigeria	Qualitative research		Individuals with SCD; Caregivers
Inusa 2021	Racial Inequalities in Access to Care for Young People Living With Pain Due to Sickle Cell Disease	United Kingdom	Expert Opinion or Commentary		
Jacob 2001	The Pain Experience of Patients With Sickle Cell Anemia	United States	Narrative Review		
Jacob 2003	Changes in Intensity, Location, and Quality of Vaso-Occlusive Pain in Children With Sickle Cell Disease	United States	Prospective descriptive	Longitudinal	Individuals with SCD
Jacob 2005	Are There Phases to the Vaso-Occlusive Painful Episode in Sickle Cell Disease?	United States	Prospective descriptive	Mixed Methods	Individuals with SCD; Caregivers
Jacob 2013	Facilitating Pediatric Patient-Provider Communications Using Wireless Technology in Children and Adolescents With Sickle Cell Disease	United States	Qualitative research		Individuals with SCD
Jacob 2013	Remote Monitoring of Pain and Symptoms Using Wireless Technology in Children and Adolescents With Sickle Cell Disease	United States	Prospective descriptive	Longitudinal	Individuals with SCD
Jean-Baptiste 2022	Individuals With Sickle Cell Disease Using SBAR as a Communication Tool: A Pilot Study	United States	Non-Randomized Experimental study		Individuals with SCD
Jenerette 2008	Successful Aging With Sickle Cell Disease: Using Qualitative Methods to Inform Theory	United States	Qualitative research		Individuals with SCD
Jenerette 2010	Health-Related Stigma in Young Adults With Sickle Cell Disease	United States	Expert Opinion or Commentary		

Jenerette 2011	Situation, Background, Assessment, and Recommendation (SBAR) May Benefit Individuals Who Frequent Emergency Departments: Adults With Sickle Cell Disease	United States	Expert Opinion or Commentary		
Jenerette 2014	An Intervention to Decrease Stigma in Young Adults With Sickle Cell Disease	United States	Randomized controlled trial		Individuals with SCD
Jha 2010	Cognitive Testing of PAINReportIt in Adult African Americans With Sickle Cell Disease	United States	Qualitative research		Individuals with SCD
Johnson 2003	Sickle Cell Disease Patients and Patient-Controlled Analgesia	United Kingdom	Cross-sectional	Mixed Methods	Individuals with SCD
Jonassaint 2021	If You Can't Assess It, How Can You Treat It? Improving Pain Management in Sickle Cell Disease	United States	Expert Opinion or Commentary		
Jones 2005	Pain Assessment in Pediatric Sickle Cell Disease	United States	Narrative Review		
Kanter 2020	Perceptions of US Adolescents and Adults With Sickle Cell Disease on Their Quality of Care	United States	Cross-sectional		Individuals with SCD
Kenyon 2012	Setting the Agenda for Quality Improvement in Pediatric Sickle Cell Disease	United States	Qualitative research		Caregivers; Clinicians
Knisely 2024	Comparison of Measures of Pain Intensity During Sickle Cell Disease Vaso-Occlusive Episodes	United States	Prospective descriptive	Secondary Analysis; Instrument Development/ Validation	Individuals with SCD
Lacerda 2014	Women With Sickle Anemia Living With Leg Ulcers and Pain	Brazil	Qualitative research		Individuals with SCD
LaMotte 2022	Understanding the Roots of Mistrust in Medicine: Learning From the Example of Sickle Cell Disease	United States	Expert Opinion or Commentary		
Lapite 2023	A Qualitative Systematic Review of Pediatric Patient and Caregiver Perspectives on Pain Management for Vaso-Occlusive Episodes in the Emergency Department	United States	Systematic/ Scoping Review		
Lattimer 2010	Problematic Hospital Experiences Among Adult Patients With Sickle Cell Disease	United States	Prospective cohort		Individuals with SCD
Liederman 2021	Exploration of Barriers and Facilitators to Optimal Emergency Department Care of Sickle Cell Disease: Opportunities for Patient-Physician Partnerships to Improve Care	Canada	Qualitative research		Individuals with SCD; Clinicians
Lin 2015	A Mixed-Methods Study of Pain-Related Quality of Life in Sickle Cell Vaso-Occlusive Crises	United States	Retrospective cohort	Mixed Methods	Individuals with SCD

Linton 2020	A Survey-Based Needs Assessment of Barriers to Optimal Sickle Cell Disease Care in the Emergency Department	United States	Cross-sectional		Individuals with SCD; Clinicians
Lopez 2007	Clinically Significant Differences in the Visual Analog Pain Scale in Acute Vasoocclusive Sickle Cell Crisis	United States	Pre-Post Measurement Study	Instrument Development/ Validation	Individuals with SCD
Lopez 2014	Edmonton Symptom Assessment System for Outpatient Symptom Monitoring of Sickle Cell Disease	United States	Pre-Post Measurement Study	Instrument Development/ Validation	Individuals with SCD
Lucchesi 2016	Physicians' Perception of Sickle-Cell Disease Pain	Brazil	Cross-sectional		Individuals with SCD; Clinicians
Luffy 2003	Examining the Validity, Reliability, and Preference of Three Pediatric Pain Measurement Tools in African-American Children	United States	Cross-sectional	Instrument Development/ Validation	Individuals with SCD
Lyn 2026	A Qualitative Study of the Lived Experiences of Pregnancy and Childbirth: Unheard Voices of Black Women With Sickle Cell Disease	United States	Qualitative research		Individuals with SCD
Maikler 2001	Childrens' and Adolescents' Use of Diaries for Sickle Cell Pain	United States	Prospective descriptive		Individuals with SCD
Masese 2019	Barriers and Facilitators to Care for Individuals With Sickle Cell Disease in Central North Carolina: The Emergency Department Providers' Perspective	United States	Cross-sectional	Mixed Methods	Clinicians
Masese 2021	A Needs Assessment of Persons With Sickle Cell Disease in a Major Medical Center in North Carolina	United States	Cross-sectional	Mixed Methods	Individuals with SCD
Matthie 2015	Sickle Cell Disease in Adults: Developing an Appropriate Care Plan	United States	Educational or Instructional		
Matthie 2016	Perceptions of Young Adults With Sickle Cell Disease Concerning Their Disease Experience	United States	Qualitative research		Individuals with SCD
Matthie 2017	Understanding the Self-Management Practices of Young Adults With Sickle Cell Disease	United States	Qualitative research		Individuals with SCD
Matthie 2019	A Qualitative Study of Chronic Pain and Self-Management in Adults With Sickle Cell Disease	United States	Qualitative research		Individuals with SCD
Maxwell 1999	Experiences of Hospital Care and Treatment-Seeking Behavior for Pain From Sickle Cell Disease: Qualitative Study	United Kingdom	Qualitative research		Individuals with SCD
McClellan 2009	Criterion and Convergent Validity for 4 Measures of Pain in a Pediatric Sickle Cell Disease Population	United States	Pre-Post Measurement Study	Instrument Development/ Validation	Individuals with SCD

Mendez	Social Determinants of Health and Treatment Center Affiliation: Analysis From the Sickle Cell Disease Implementation Consortium Registry	United States	Cross-sectional	Secondary Analysis	Individuals with SCD
Meraya 2026	Clinical, Humanistic, and Economic Burden of Sickle Cell Disease in the Jazan Region, Saudi Arabia	Saudi Arabia	Cross-sectional		Individuals with SCD
Middleton 2018	Communication With Children About Sickle Cell Disease: A Qualitative Study of Parent Experience	United Kingdom	Qualitative research		Caregivers
Miles 2020	Obstacles to Use of Patient Expertise to Improve Care: A Co-Produced Longitudinal Study of the Experiences of Young People With Sickle Cell Disease in Non-Specialist Hospital Settings	United Kingdom	Qualitative research	Longitudinal	Individuals with SCD
Moore 2022	Treatment of Acute Pain Episodes: A Prisoner's Dilemma	United States	Expert Opinion or Commentary		
Morrison 1989	Pain Management in the Child With Sickle Cell Disease	United States	Educational or Instructional		
Mulchan 2024	Initial Evaluation of an Intervention to Address Provider Implicit Bias in Pediatric Sickle Cell Disease Pain Care: A Mixed Methods Pilot Study	United States	Randomized Experiment		Clinicians
Munung 2026	Barriers to Sickle Cell Disease Care: A Biopsychosocial Analysis Mapped to the Standards of Care Guidelines by the Sickle Pan African Research Consortium	Multiple (Ghana, Malawi, Nigeria, South Africa)	Systematic/ Scoping Review		
Myrvik 2013	Clinically Meaningful Measurement of Pain in Children With Sickle Cell Disease	United States	Prospective descriptive	Instrument Development/ Validation	Individuals with SCD
Myrvik 2015	A Comparison of Pain Assessment Measures in Pediatric Sickle Cell Disease: Visual Analog Scale Versus Numeric Rating Scale	United States	Prospective descriptive	Instrument Development/ Validation	Individuals with SCD
Neul 2003	Developmental Concepts of Disease and Pain in Pediatric Sickle Cell Patients	United States	Cross-sectional		Individuals with SCD; Caregivers
Neumayr 2010	Chart Card: Feasibility of a Tool for Improving Emergency Department Care in Sickle Cell Disease	United States	Randomized controlled trial		Individuals with SCD; Caregivers
Nogueira 2026	Invisible in the System: Fragmented Data and Territorial Inequalities in Sickle Cell Disease in Brazil	Brazil	Cross-sectional		Individuals with SCD

Nwora 2024	How Young Adults With Sickle Cell Disease Define "Being a Good Patient" in the Adult Healthcare System	United States	Cross-sectional	Mixed Methods	Individuals with SCD
O'Brien 2024	Cognitive Considerations for Adults With Sickle Cell Disease Completing the Brief Pain Inventory	United States	Cross-sectional	Secondary Analysis	Individuals with SCD
O'Brien 2025	The Use of Abstract Animations and a Graphical Body Image for Assessing Pain Outcomes Among Adults With Sickle Cell Disease.	United States	Cross-sectional	Baseline Data of Clinical Trial; Instrument Development/ Validation	Individuals with SCD
O'Connor 2014	Attitudes Among Healthcare Providers and Patients Diagnosed With Sickle Cell Disease: Frequent Hospitalizations and Stressors	United States	Qualitative research		Individuals with SCD
Obasohan 2026	A Multidimensional Digital Approach to Pain Assessment in Sickle Cell Disease: A Feasibility Study in Ghana	Ghana	Cross-sectional		Individuals with SCD
Ohemeng-Tinyase 2025	"Her Hospital Card Is Missing": A Qualitative Investigation Into the Facilitators of and Barriers to Formal Healthcare Use Among Sickle Cell Patients in Ghana	Ghana	Qualitative research		Individuals with SCD; Caregivers
Okagbare 2025	Your Pain and Mine: The Mismatch Between Pain Expression and Perception of Patients With Sickle Cell Disease in the UK	United Kingdom	Qualitative research		Clinicians
Oliveira 2019	Quality of Life in Pre-Adolescent Children With Sickle Cell Disease in Brazil	Brazil	Cross-sectional	Secondary Analysis	Individuals with SCD
Oluwole 2025	Experiences With a Multicomponent Digital Behavioral Pain Management Intervention for Adults With Sickle Cell Disease: Qualitative Analysis of the CARISMA Trial	United States	Qualitative research		Individuals with SCD
Owoo 2022	The Lived Experiences of Caregivers of Children With Sickle Cell Disease: A Phenomenological Study	United States	Qualitative research		Caregivers
Oyedeji 2020	Improving the Quality of Care for Adolescents and Adults With Sickle Cell Disease-It's a Long Road	United States	Expert Opinion or Commentary		
Oyedeji 2025	"I Can't Let It Stop Me": Perspectives on Aging From Older Adults With Sickle Cell Disease	United States	Qualitative research		Individuals with SCD
Panepinto 2012	Development of the PedsQL Sickle Cell Disease Module Items: Qualitative Methods	United States	Qualitative research	Instrument Development/ Validation	Individuals with SCD; Caregivers

Pantaleao 2019	Caregiver Factors Related to Emergency Department Utilization for Youth With Sickle Cell Disease	United States	Cross-sectional		Caregivers
Phillips 2022	Perspectives of Individuals With Sickle Cell Disease on Barriers to Care	United States	Cross-sectional	Mixed Methods	Individuals with SCD
Phillips 2023	Patient and Family Opioid Decision-Making for Pain Management in Sickle Cell Disease: A Qualitative Study	United States	Qualitative research		Individuals with SCD; Caregivers
Poku 2017	Adolescents' Experiences of Living With Sickle Cell Disease: An Integrative Narrative Review of the Literature	United Kingdom	Integrative Review		
Porter 2012	Sickle Cell Disease Patients' Perceptions of Emergency Department Pain Management	United States	Prospective cohort		Individuals with SCD
Porter 2017	Pediatric to Adult Care Transition: Perspectives of Young Adults With Sickle Cell Disease	United States	Qualitative research		Individuals with SCD
Power-Hays 2020	When Actions Speak Louder Than Words - Racism and Sickle Cell Disease	United States	Expert Opinion or Commentary		
Prince 2024	"Buprenorphine, It Works so Differently": Adults With Sickle Cell Disease Describe Transitioning to Buprenorphine for Treatment of Chronic Pain	United States	Qualitative research		Individuals with SCD
Rao 2022	A Novel Method for Digital Pain Assessment Using Abstract Animations: Human-Centered Design Approach	United States	Qualitative research	Instrument Development/ Validation	Individuals with SCD; Clinicians
Ratanawongsa 2009	Health Care Provider Attitudes Toward Patients With Acute Vaso-Occlusive Crisis Due to Sickle Cell Disease: Development of a Scale	United States	Cross-sectional	Instrument Development/ Validation	Individuals with SCD; Clinicians
Reich 2023	An Integrative Review: The Evolution of Provider Knowledge, Attitudes, Perceptions and Perceived Barriers to Caring for Patients With Sickle Cell Disease 1970-Now.	United States	Integrative Review		
Reich 2024	Attitudes and Beliefs of Nurses and Nurse Assistants Toward Patients With Sickle Cell Disease: A Mixed Methods Study.	United States	Cross-sectional	Mixed Methods	Clinicians
Renedo 2019	Not Being Heard: Barriers to High Quality Unplanned Hospital Care During Young People's Transition to Adult Services - Evidence From 'this Sickle Cell Life' Research	United Kingdom	Qualitative research	Longitudinal	Individuals with SCD
Renedo 2020	Understanding the Health-Care Experiences of People With Sickle Cell Disorder Transitioning	United Kingdom	Qualitative research	Longitudinal	Individuals with SCD

	From Paediatric to Adult Services: This Sickle Cell Life, a Longitudinal Qualitative Study				
Rivas Berger 2024	The Impact of a Single Music Therapy Session on Pain Perception of Patients With Sickle Cell Disease	United States	Non-Randomized Experimental study		Individuals with SCD
Rouse 2004	Paradigms and Politics: Shaping Health Care Access for Sickle Cell Patients Through the Discursive Regimes of Biomedicine	United States	Qualitative research		
Rouse 2011	Informing Choice or Teaching Submission to Medical Authority: A Case Study of Adolescent Transitioning for Sickle Cell Patients	United States	Qualitative research		
Rousseau 2020	Utilization, Financial Outcomes and Stakeholder Perspectives of a Re-Organized Adult Sickle Cell Program	United States	Non-Randomized Experimental study	Mixed Methods	Individuals with SCD; Clinicians
Ruan 2026	Barriers and Facilitators to Healthcare Utilization Amongst People Living With Sickle Cell Disease in the United States: A Scoping Review	United States	Systematic/ Scoping Review		
Sasmaz 2026	Between Crises and Care: Childhood Realities With Sickle Cell Anemia: A Qualitative Study	Turkey	Qualitative research		Individuals with SCD
Savitt 2014	Use of the Word "Crisis" in Sickle Cell Disease: The Language of Sickle Cell	United States	Expert Opinion or Commentary		
Schiavenato 2013	Pain Assessment During a Vaso-Occlusive Crisis in the Pediatric and Adolescent Patient: Rethinking Practice	United States	Expert Opinion or Commentary		
Schlenz 2025	Barriers and Facilitators to Comprehensive Pediatric Sickle Cell Care: A Qualitative Study	United States	Qualitative research		Individuals with SCD; Caregivers
Siewny 2024	Impact of an Individualized Pain Plan to Treat Sickle Cell Disease Vaso-Occlusive Episodes in the Emergency Department	United States	Non-Randomized Experimental study		Individuals with SCD; Clinicians
Sil 2026	Chronic Pain Lived Experience of Pediatric Sickle Cell Disease: A Qualitative Study	United States	Qualitative research		Individuals with SCD; Caregivers
Singh 2016	Improving Emergency Providers' Attitudes Towards Sickle Cell Patients in Pain	United States	Non-Randomized Experimental study		Clinicians
Singh 2020	What Is the Future of Patient Reported Outcomes in Sickle Cell Disease?	United States	Narrative Review		
Sisler 2022	Satisfaction and Access to Care for Adults and Adolescents With Sickle Cell Disease: ASCQ-Me Quality of Care and the SHIP-HU Study	United States	Cross-sectional	Baseline Data of Clinical Trial	Individuals with SCD

Smith 2005	Understanding Pain and Improving Management of Sickle Cell Disease: The PiSCES Study	United States	Prospective cohort	Longitudinal	
Smith 2011	Frequently Asked Questions by Hospitalists Managing Pain in Adults With Sickle Cell Disease	United States	Educational or Instructional		
Smith 2014	Treating Pain in Sickle Cell Disease With Opioids: Clinical Advances, Ethical Pitfalls	United States	Expert Opinion or Commentary		
Smith 2022	Structural Racism and Impact on Sickle Cell Disease: Sickle Cell Lives Matter	United States	Expert Opinion or Commentary		
Smith 2026	Criterion Validity of the Functional Status and Pain Assessment Scale Versus Pain and Length of Stay in Hospitalized Adults With SCD	United States	Prospective descriptive	Instrument Development/ Validation; Longitudinal	Individuals with SCD
Sporrer 1994	Pain in Children and Adolescents With Sickle Cell Anemia: A Prospective Study Utilizing Self-Reporting	United States	Prospective descriptive		Individuals with SCD
Stefanatou 1997	Depiction of Pain in the Self-Drawings of Children With Sickle Cell Disease	United Kingdom	Cross-sectional	Mixed Methods	Individuals with SCD; Caregivers
Stewart 2021	"Pain Is Subjective": A Mixed-Methods Study of Provider Attitudes and Practices Regarding Pain Management in Sickle Cell Disease Across Three Countries	Multiple (Cameroon, Jamaica, US)	Cross-sectional	Mixed Methods	Clinicians
Stinson 2003	Pain Management in Children With Sickle Cell Disease	Canada	Educational or Instructional		
Strickland 2001	Use of Focus Groups for Pain and Quality of Life Assessment in Adults With Sickle Cell Disease	United States	Qualitative research		Individuals with SCD; Caregivers
Tanabe 2010	Emergency Department Sickle Cell Assessment of Needs and Strengths (ED-SCANS), a Focus Group and Decision Support Tool Development Project	United States	Qualitative research	Instrument Development/ Validation	Individuals with SCD; Clinicians
Tanabe 2011	Understanding and Meeting the Hospitalist's Challenge: Caring for Adults With Sickle Cell Disease	United States	Expert Opinion or Commentary		
Tanabe 2013	Care of Children With Sickle Cell Disease in the Emergency Department: Parent and Provider Perspectives Inform Quality Improvement Efforts	United States	Qualitative research	Mixed Methods	Caregivers; Clinicians
Thomas 2000	Cognitive Behavioural Therapy in Pain Management for Sickle Cell Disease	United Kingdom	Randomized controlled trial		Individuals with SCD
Thomas 2002	The Psychosocial Experience of People With Sickle Cell Disease and Its Impact on Quality of Life: Qualitative Findings From Focus Groups	United Kingdom	Qualitative research		Individuals with SCD

Thomas 2006	Communication Skills and Cultural Awareness Courses for Healthcare Professionals Who Care for Patients With Sickle Cell Disease	United Kingdom	Non-Randomized Experimental study		Caregivers; Clinicians
Todd 2006	Sickle Cell Disease Related Pain: Crisis and Conflict	United States	Case report		
Treadwell 2002	Using Quality Improvement Strategies to Enhance Pediatric Pain Assessment	United States	Non-Randomized Experimental study		Individuals with SCD; Caregivers; Clinicians
Treadwell 2020	Health Care Disparities Among Adolescents and Adults With Sickle Cell Disease: A Community-Based Needs Assessment to Inform Intervention Strategies	United States	Cross-sectional	Mixed Methods	Individuals with SCD; Clinicians
Turnbull 2026	Development of a Novel Patient-Reported Outcome Diary to Capture and Monitor Home-Managed Pain Crises in Patients With Sickle Cell Disease	United States	Qualitative research	Instrument Development/ Validation; Mixed Methods	Individuals with SCD
Udezue 2005	Observations on the Management of Acute Pain Crisis in Adult Sickle Cell Disease in Eastern Saudi Arabia	Saudi Arabia	Retrospective cohort		Individuals with SCD
Umeh 2017	The Psychosocial Impact of Leg Ulcers in Patients With Sickle Cell Disease: I Don't Want Them to Know My Little Secret	United States	Qualitative research	Secondary Analysis; Mixed Methods	Individuals with SCD
Varni 2020	Cognitive Functioning, Patient Health Communication, and Worry Mediate Pain Predictive Effects on Health-Related Quality of Life in Youth With Sickle Cell Disease	United States	Cross-sectional		Individuals with SCD
Walco 1990	Pain in Children and Adolescents With Sickle Cell Disease: A Descriptive Study	United States	Prospective descriptive		Individuals with SCD
Waters 1995	Pain From Sickle-Cell Crisis	United Kingdom	Cross-sectional		Individuals with SCD; Clinicians
Weisberg 2012	What's in a Number?	United States	Expert Opinion or Commentary		
Weisberg 2013	"I'm Talking About Pain": Sickle Cell Disease Patients With Extremely High Hospital Use	United States	Qualitative research		Individuals with SCD
Wellington 2010	Somatization in the Conceptualization of Sickle Cell Disease	United States	Cross-sectional		Individuals with SCD
Wesley 2016	Caregiver Perspectives of Stigma Associated With Sickle Cell Disease in Adolescents	United States	Qualitative research		Caregivers
While 2004	Living With Sickle Cell Disease: The Perspective of Young People	United Kingdom	Cross-sectional	Mixed Methods	Individuals with SCD

White 2021	Content Validation of a Self-Report Daily Diary in Patients With Sickle Cell Disease	United States	Qualitative research	Instrument Development/ Validation	Individuals with SCD
White 2021	Content Validation of Observer-Reported Sickle Cell Pain Diaries (SCPD-CS and SCPD-CN): Results From Interviews With Caregivers	United States	Qualitative research	Instrument Development/ Validation	Caregivers
Wilkie 2010	Patient-Reported Outcomes: Descriptors of Nociceptive and Neuropathic Pain and Barriers to Effective Pain Management in Adult Outpatients With Sickle Cell Disease	United States	Cross-sectional		Individuals with SCD
Williams-Gray 2015	Challenges and Resilience in the Lives of Adults With Sickle Cell Disease	United States	Qualitative research		Individuals with SCD
Wright 2009	Barriers to Effective Pain Management in Sickle Cell Disease	United Kingdom	Narrative Review		
Yeung 2024	Pain Management in Sickle Cell Anemia as a Prisoner's Dilemma: A Qualitative Study of Emergency Medicine and Internal Medicine Physicians	United States	Cross-sectional	Mixed Methods	Clinicians
Young 2020	Let Their Voices Be Seen	United States	Qualitative research		Individuals with SCD
Young 2025	Sickle Cell Journeys: Healthcare Providers at the Front Lines	United States	Qualitative research		Clinicians
Zabalia 2011	The Body Posture Pain Scale: Assessment of Pediatric Sickle Cell Pain Intensity.	France	Cross-sectional	Instrument Development/ Validation	Individuals with SCD
Zempsky 2009	Treatment of Sickle Cell Pain: Fostering Trust and Justice	United States	Expert Opinion or Commentary		
Zempsky 2011	Pain Scores: Are They Used in Sickle Cell Pain?	United States	Retrospective cohort		Individuals with SCD
Zempsky 2013	Daily Changes in Pain, Mood and Physical Function in Youth Hospitalized for Sickle Cell Disease Pain	United States	Prospective descriptive		Individuals with SCD
Zerdan 2025	Highlighting Healthcare Disparities in Sickle Cell Disease Management in Resource-Constrained Settings: A Cross-Sectional Study in Lebanon	Lebanon	Cross-sectional		Individuals with SCD; Caregivers; Clinicians
Zwicker 2026	Hospitalization Through Families' Eyes: Comparing Inpatient Care Quality for Children With Sickle Cell Disease and Cystic Fibrosis in Canada	Canada	Retrospective cohort		Individuals with SCD; Caregivers