Barriers and facilitators to urgent and emergency care-seeking during vaso-occlusive crises in adults with sickle cell disease: a systematic review

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ABSTRACT

This systematic review examined patient, social, structural and healthcare factors influencing urgent or emergency care among adults with sickle cell disease (SCD) during vaso-occlusive crises (VOCs). No prior review has comprehensively synthesised factors shaping pre-arrival care-seeking in this context. The review was pre-registered on PROSPERO (CRD42023478012).

We searched PubMed and Web of Science, from inception to 2nd December 2025 and CINAHL and Embase from inception to 16 June 2026, for quantitative, qualitative and mixed-methods studies examining factors influencing pre-arrival urgent care-seeking during acute VOCs in adults with SCD. We conducted a narrative synthesis, grouping similar factors and coding them as barriers or facilitators across three outcome domains: care-seeking avoidance, delayed care-seeking and willingness to seek acute care.

Twelve studies published 2014 - 2025 met the inclusion criteria. Nine were conducted in the United States, two in Canada and one in England with none from low- and middle-income countries were identified. The most consistent barriers to acute care-seeking, particularly delayed or avoided presentation, were anticipated negative emergency department experiences, including stigma, discrimination, disbelief of pain and low confidence in timely analgesia or protocol-based care. Delays were also associated with prolonged home management, higher escalation thresholds and practical constraints such as insurance, transport and competing responsibilities. Evidence on willingness to seek acute care was limited. Methodological quality varied with concerns about representativeness, missing data and confounding in quantitative studies. Improving timely care-seeking may require

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more equitable, protocol-driven crisis care alongside efforts to reduce stigma and improve patient trust in acute care settings.

Keywords: Sickle Cell Disease, vaso-occlusive crises, vaso-occlusive pain, emergency medicine, patient care, care-seeking

INTRODUCTION

Painful vaso-occlusive crises (VOCs) are a leading cause of emergency visits and unplanned hospitalisation for people with sickle cell disease (SCD).[1,2] These episodes, characterised by sudden and severe pain, may lead to chronic organ damage, disability and mortality if urgent care is delayed or inadequate. Timely and effective crisis care remains a central challenge in efforts to reduce the morbidity and mortality associated with SCD.[3]

Several reviews in the past decade have examined elements of the acute care pathway for people with SCD. One review found that factors associated with emergency services utilisation among SCD patients included patient characteristics such as age, insurance status, disease severity and psychological factors.[4] Another review found that stigma from healthcare providers and institutions undermines trust and can deter patients with SCD from seeking care when they experience pain.[5] A further review of emergency department (ED) protocols for VOCs in adults found that structured pathways can reduce time to first opioid administration, improve pain relief and shorten length of stay for those who reach hospital.[6] While these reviews highlight important aspects of hospital care for individuals with SCD, they primarily focus on patients who already accessed services and on care processes after arrival. However, limited synthesis has examined the decision-making processes that

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occur prior to presentation, particularly how these factors influence delays, avoidance and willingness to seek care.

It therefore remains unclear how multilevel factors, including patient, social, structural and healthcare-system factors shape pre-hospital care-seeking behaviours during acute VOCs in adults with SCD, including outcomes such as willingness to seek care and timely presentation. To our knowledge, no published review has comprehensively synthesised these pre-arrival decision-making processes. To address this gap, we conducted a systematic review to identify, appraise and synthesise quantitative and qualitative evidence on determinants of urgent and emergency care-seeking among adults with SCD during acute VOCs.

The primary research question for this review is "What patient, social, structural and healthcare-system factors influence whether and how quickly an adult experiencing a VOC seeks urgent or emergency care?" By integrating evidence across settings and disciplines, the review aims to inform the design of more equitable and timely crisis care pathways and to support efforts to improve acute SCD care and reduce avoidable harm.

METHODS

Search strategy

We pre-registered this systematic review on PROSPERO (CRD42023478012) and we report it in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) 2020 statement.[7] We provide the completed PRISMA checklist in Supplementary Table 1.

On 2 December 2025, we systematically searched PubMed and Web of Science Core Collection from database inception to the search date for studies that examined

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barriers and facilitators influencing timely use of ED and other urgent care services during VOCs in adults with SCD. Supplementary searches of Embase (Ovid) and CINAHL (EBSCOhost) were conducted on 16 June 2026 using the same search strategy and eligibility criteria. We applied no geographical or date restrictions. We organised search terms into three concept groups: 1) SCD terms, 2) crisis terms and 3) care-seeking terms, with the Boolean operators 'AND' and 'OR' used. We pilot tested and refined search terms using terminology from published reviews.[4–6] The full database search strategies are reported verbatim in Supplementary Table 2. We imported search records into Rayyan and removed duplicates.[8] Three reviewers (SW, MA, and KI) independently screened titles and abstracts, resolving disagreements through discussion. Four reviewers (SW, MA, KI, and YW) then assessed full-text articles for eligibility, resolving conflicts through discussion. Disagreements were relatively infrequent and were resolved through discussion until consensus was reached and formal counts of reviewer disagreements were not prospectively recorded.

Inclusion and exclusion criteria

We included quantitative, qualitative and mixed method studies that recruited adults with SCD, defined as individuals 18 years and older. However, mixed-age studies were eligible where they included adults and reported relevant care-seeking evidence. Where findings were not disaggregated by age, they were retained in the narrative synthesis as mixed-age but were not treated as definitive evidence specific to adults. Eligible participants were required to report experiences or perceptions of acute painful VOCs prompting urgent or emergency care. Eligible care settings included ED, urgent care or walk-in services, emergency medical services or ambulance care, acute day-hospital services functioning as unscheduled alternatives to ED care, and unplanned

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hospital admissions. Only studies published in English were eligible for inclusion. We excluded studies that recruited paediatric patients only, animal studies, and studies that focused solely on in-hospital management of SCD VOCs or on routine or scheduled outpatient care following initial presentation. We also excluded studies that did not report primary empirical data, including reviews, editorials and conference abstracts.

Data extraction

Four reviewers (SW, MA, KI, and YW) independently extracted data from included studies using a standardised Excel spreadsheet. Extracted variables included study characteristics, population and setting details, comparison groups, factors of interest, outcome measures and key findings relevant to pre-arrival care-seeking. The data extraction form was piloted on a subset of studies and refined as needed. We extracted key findings as either quantitative estimates e.g., adjusted regression coefficients or qualitative themes. Following independent extraction, the reviewers discussed their extracted data and resolved discrepancies through discussion and consensus to agree on the final data extracted for synthesis.

Data synthesis

Due to heterogeneity in study designs, reported factors and outcome measures, we did not conduct a meta-analysis.[9] We therefore undertook a narrative synthesis, guided by established methodological frameworks.[9] Studies were grouped according to pre-arrival care-seeking outcomes, including delayed care-seeking, care avoidance and willingness to seek urgent care. For this review, willingness to seek acute care referred to reported intention, attitude or preference regarding seeking urgent or emergency care during a VOC. It was not defined using a specific time frame and

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therefore not interpreted as evidence of actual or timely presentation. To facilitate comparison across studies, we standardised extracted concepts by collapsing similar constructs relating to factors influencing care-seeking and associated outcomes.[10] Findings from studies with mixed-aged populations and no age specific data informed the synthesis but not the conclusions about adults. We then coded extracted concepts as either a barrier or facilitator and explored relationships between them and the full coding set is available in Supplementary Table 3-5.

Risk of bias

Due to the design and methodological heterogeneity, we assessed risk of bias using the 2018 version of the Mixed Methods Appraisal Tool (MMAT).[11,12] The MMAT applies five design-specific criteria to qualitative, quantitative randomised, quantitative non-randomised, quantitative descriptive and mixed-methods studies. The mixed-methods studies were assessed using qualitative, relevant quantitative and mixed-methods criteria. Two reviewers (JF and AD) independently assessed each included study using the MMAT, resolving disagreements through discussion. Appraisal findings informed interpretation but were not used to exclude studies. The full risk of bias assessments are provided in Supplementary Table 6.

RESULTS

Search results

The systematic search identified 2,795 records (PubMed n = 792, Web of Science n = 826, Embase n = 1,049, CINAHL n = 128) of which 1,883 remained after duplicate removal. The supplementary searches yielded 968 additional records, all of which were excluded during title and abstract screening. Following title and abstract screening, 44 articles progressed to full-text review. Of these, 32 were excluded,

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leaving 12 studies that met the inclusion criteria. The study selection process is summarised in Figure 1.

[insert Figure 1 PRISMA flowchart here]

Study characteristics

Table 1 summarises the characteristics of the 12 studies, published between 2014 and 2025. Most studies were conducted in the USA (9/12)[13–21], with two studies from Canada (2/12)[22,23] and one from England (1/12)[24]. The evidence base comprised predominantly of cross-sectional surveys and qualitative studies, with several mixed-methods designs. Study populations included adults with SCD experiencing VOCs, although some studies included adolescents or mixed-age samples. Outcomes examined factors influencing urgent care-seeking behaviour, including delays or avoidance of emergency care, willingness to seek care and patient-reported barriers and facilitators. Most included studies examined ED care-seeking experiences and ED utilisation. A smaller number also reported experiences of alternative urgent-care pathways, including ambulatory acute care and short-stay services.

[Insert study characteristics Table 1 here]

The findings from the narrative synthesis are presented across three pre-arrival domains: 1) avoidance of care-seeking (n = 5)[14,18,21,23,24] 2) delayed care-seeking (n = 8)[13–15,17,19–21,23] and 3) willingness to seek acute care (n = 3)[16,22,23]. Each domain included between three and five sub-themes. Studies often contributed to multiple subthemes and therefore sub-theme counts are not mutually exclusive. The full coding framework is provided in Supplementary Table 3-5.

Avoidance of seeking care (n = 5)

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Across this outcome domain, factors operated primarily as barriers and clustered into three sub-themes: 1) previous negative acute-care experiences (including unwelcoming or destabilising care environments[23,24] and poor continuity of care),[14,18,21,23,24] 2) perceptions of stigmatisation such as racism and drug-seeking behaviours and 3) practical constraints discouraging seeking emergency care.[23]

Participants described reluctance to attend emergency services following previous negative encounters and in anticipation of not being believed or being stigmatised when presenting with pain. For example, a USA survey found that previously negative ED experiences influenced 52% of respondents' decision to avoid seeking care.[18] In a mixed methods study, participants described being stigmatised as "drug seeking", experiencing disbelief about their pain and receiving inadequate pain control.[14] Concerns about post-discharge care also contributed to reluctance to return, including leaving without clear discharge instructions, prescriptions for pain medication or follow up arrangements.[14] Similarly, an interview study in Canada reported racial stigma when seeking emergency care for pain crises.[23]

Two studies further linked reluctance to attend hospital to specific features of the care environment. In Canada, participants described low comfort levels and distressing factors including unpleasant smells and sounds.[23] In England, a study examined young people's experiences during transition from paediatric to adult services. Participants described feeling out of place in adult wards, repeated moves between wards, delays in support for basic needs and experiences of not being treated with dignity.[24] One study highlighted the practical barriers that made hospital attendance difficult even when symptoms were severe, with participants describing childcare responsibilities and concerns about difficult intravenous access as factors that discouraged seeking hospital care.[23]

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Delayed seeking of care (n = 8)

Across this outcome domain, most factors operated as barriers and were clustered into three subthemes 1) anticipated negative ED care experiences and reduced confidence in receiving timely care[13–15,17,19–21] 2) prolonged home management with higher thresholds for deciding care was needed[13,17,21,23] and 3) practical access constraints and competing responsibilities[17,19,23].

Across studies, participants described delaying attendance when they expected to be disbelieved, stereotyped or experience delayed treatment.[13–15,17,20,21,23] For example, a USA survey found that higher perceived stigma were associated with increased odds of delaying ED care, whereas higher healthcare satisfaction was associated with reduced odds of delay.[13] Qualitative data further described stigma linked to assumptions of "drug-seeking" and demeaning interactions that undermined confidence that pain would be taken seriously.[14,15,21] Participants also emphasised burdensome processes such as long waiting times, the need to explain sickle cell pain and advocate for appropriate treatment and the perceived absence or inconsistent use of crisis protocols.[14,23] Interview data collected during emergency visits similarly described being treated as "drug-seeking" and experiencing long waits which discouraged timely use of emergency services. [20]

Delayed care-seeking was also linked to efforts to manage pain at home until symptoms were perceived as severe.[13,17,21,23] For example, in a mixed methods study of young adults, most respondents reported attempting to manage pain at home and waiting until pain levels were very high before seeking care.[17] Qualitative accounts described a deliberate pattern of exhausting home management strategies before attending the ED, alongside concerns about needing to appear visibly unwell to be taken seriously, which reinforced delay.[21] In Canadian interviews, participants

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described weighing symptom persistence and intensity against anticipated barriers in hospital and some reporting staying home when they lacked the energy or support to advocate for themselves.[23] Participants also described limited or inconsistent guidance on crisis management and when to seek help, which could prolong home management and delay escalation to urgent care.[23]

Several studies indicated that delays were also shaped by access and logistical constraints.[17,19,23] In young adults, barriers included lack of insurance and transport constraints, such as travel time and difficulty accessing the ED.[17] In a larger needs assessment study, respondents who reported delaying ED attendance also identified insurance-related financial barriers.[19] Interviews also highlighted practical responsibilities that made hospital attendance difficult, including lack of childcare in the event of admission.[23]

Willingness to seek acute care (n = 3)

Only three studies examined factors associated with willingness to seek acute care during vaso-occlusive pain. These factors related to confidence in acute-care delivery, individual attitudes and intentions towards seeking care and practical access to alternative urgent care pathways. Willingness was related to, but distinct from, avoidance and delayed care-seeking because it captured reported intention, attitude or preference rather than actual care-seeking behaviour or the timing of presentation. The findings operated at two levels 1) features of institutional care delivery that increased confidence in receiving appropriate treatment and 2) individual intentions shaped by prior service use, alongside practical constraints on accessing alternative urgent pathways.[16,22,23] In qualitative interviews, participants reported greater willingness to attend when they anticipated consistent and

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supported care including the ability to self-advocate and confidence that staff would follow established crisis management protocols.[23] Survey evidence similarly indicated that willingness was higher among individuals with more favourable attitudes toward ED use and those with more frequent prior ED use, while stigma and prior ED experiences were not significant predictors in adjusted models.[16] In contrast, barriers to using a short-stay unit pathway reflected practical access constraints rather than treatment expectations, with lack of service awareness and travel distance identified as the most common obstacles.[22]

Risk of Bias Assessment

Methodological quality was appraised for all included studies, with results of these assessments presented in Supplementary Table 6. All studies had clear research questions and collected data capable of addressing them. Common concerns included limited sample representativeness, incomplete outcome data, indeterminate non-response bias and insufficient control of confounding in some quantitative studies. Qualitative studies generally met the MMAT criteria. In mixed-methods studies concerns arose mostly from their quantitative components although integration criteria were generally met. Two studies drew on the same dataset, such as Sickle Cell Disease Implementation Consortium (SCDIC) data and should not be treated as entirely independent evidence.[18,19] Findings from studies with concerns across applicable MMAT criteria were interpreted cautiously in relation to findings from other studies.

DISCUSSION

This systematic review identified 12 studies examining factors influencing timely use of EDs and other urgent care services among adults with SCD during VOCs, with

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most evidence originating from the USA. Studies most consistently linked delayed or avoided presentation to expectations of negative emergency care encounters, including stigma, disbelief and inadequate pain management, alongside concerns about limited continuity of care after discharge. A second pattern reflected preferences for prolonged home management and high pain thresholds prior to seeking care, alongside uncertainty about when symptoms required urgent escalation. Practical constraints, such as insurance-related barriers, transport difficulties and competing responsibilities e.g., work or childcare were less frequently emphasised. Evidence on willingness to seek care was limited and suggested it was greater when patients anticipated reliable, protocol-based care and could access alternative urgent pathways, such as ambulatory acute care units and other short-stay services that provide unscheduled management of VOCs outside traditional EDs. Taken together, these findings suggest that anticipated negative emergency care experiences including stigma, disbelief and concerns about pain management, may contribute to delayed or avoided presentation. However, evidence concerning willingness to seek care was limited and the only included study examining perceived clinician stigma as a predictor of willingness found no statistically significant association after adjustment.[16] This finding should be interpreted separately from evidence on delayed or avoided care because willingness was measured as a reported intention or attitude rather than the timing of actual presentation. Associations between prior ED use and care-seeking were also inconsistent across cross-sectional studies, suggesting that previous use may reflect disease burden, familiarity with services or prior care experiences rather than acting as an independent barrier or facilitator.[13,16]

Limitations of our review

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As with all systematic reviews, several limitations should be considered when interpreting these findings. First, although we searched major biomedical and multidisciplinary databases (PubMed, Web of Science, CINAHL and Embase), relevant studies indexed in other databases may not have been captured.[25–27] However, search terms were piloted and refined to maximise retrieval. Second, heterogeneity in study designs and outcomes examined precluded meta-analysis. Third, restricting inclusion to peer-reviewed empirical articles and excluding grey literature and conference abstracts may have under-represented emerging or unpublished evidence. Finally, inclusion of mixed-age samples where adult-specific findings were not clearly disaggregated reduced the specificity of conclusions for adults and limited comparison by setting and countries.

Several limitations were also evident within the underlying evidence base. Quantitative findings were commonly affected by limited sample representativeness, while some studies had incomplete outcome data, indeterminate non-response bias or insufficient control of confounding. Qualitative studies generally met the applicable MMAT criteria, although findings often arose from small, geographically restricted samples. In mixed-methods studies, concerns related primarily to the quantitative components while integration criteria were generally met however, the rationale for using mixed methods was unclear in one study. We therefore interpreted findings cautiously where they depended on non-representative samples, incomplete data or inadequately controlled analyses and considered whether other studies supported similar findings.

Several included studies[14,18,19,23,24] contained mixed-age samples and age-specific findings were inconsistently reported. Findings that could not be disaggregated by age informed the contextual synthesis but were not treated as definitive evidence

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specific to adults. Consequently, we could not determine whether barriers and facilitators to urgent care-seeking differed systematically across age groups. Future research should examine these relationships, particularly during transition to adult services. In addition, research is also needed to assess whether these findings are transferable to low- and middle- income countries, as no studies from these settings were identified in this review.

Patients and members of the public were not formally involved in the design, conduct, analysis, or interpretation of this review. However, several members of the author team had prior experience of patient-centred research, public engagement, advocacy, and knowledge-exchange activities relating to the experiences of people living with SCD. While these activities informed the authors' understanding of the topic area, they did not constitute formal patient and public involvement within the review process. Future research would benefit from incorporating patient and public involvement to help ensure that research priorities and interpretations reflect the perspectives of people living with SCD.

Strengths of our review

While these limitations should be kept in mind, this review also has several strengths. First, we used a transparent and reproducible approach, including pre-registration with PROSPERO and reporting in line with PRISMA guidelines, alongside multi-reviewer screening and independent data extraction with disagreements resolved through discussion. Second, by synthesising quantitative, qualitative and mixed-methods evidence within a common framework of pre-arrival outcomes (avoidance, delayed and willingness to seek acute care), the review provides a coherent account of how multiple influences shape urgent care-seeking during VOC pain. Finally, the inclusion of studies from multiple countries and care

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settings, without restriction by publication date, maximised the breadth of evidence allowing identification of patterns, inconsistencies and gaps in the available evidence regarding urgent and emergency care-seeking among adults with SCD. Together, these strengths support the robustness of the review and its contribution to understanding urgent care-seeking behaviour in SCD.

Findings in context of existing literature

This review provides new insight into how anticipated stigma, prior care experiences and uncertainty around care pathways shape pre-arrival decision-making for urgent care in SCD. Previous research has largely focused on patterns of ED utilisation or in-department care, with less attention to the decision-making processes preceding presentation.[5,28,29] By integrating evidence across delayed care-seeking, avoidance and willingness to seek care, we show how escalation thresholds, prolonged home management and structural constraints interact to influence when and whether patients present during VOC pain episodes.

These findings build on prior work showing that stigma and negative care experiences discourage help-seeking and are linked to delayed or avoided care in chronic pain and SCD populations.[5,28,29] For example, a systematic review of SCD stigma identified impacts on patient and provider relationships and care-seeking behaviours, which aligns with our synthesis that anticipated disbelief, discrimination and low trust contribute to delayed and avoided presentation for vaso-occlusive pain.[5]

Similarly, previous reviews of ED utilisation in SCD have emphasised the role of sociodemographic, clinical and system-level factors, aligning with our finding that practical access constraints and competing responsibilities also influenced whether

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and when people sought urgent care.[30] In addition, evidence that racial and ethnic disparities persist in ED analgesia provides important context for why some patients anticipate poor pain management and delay attendance, reinforcing the central role of trust identified in our synthesis.[31]

Importantly, our review extends this literature by shifting focus from overall ED utilisation or in-department care to the decision to seek care and timing of presentation. This perspective highlights upstream influences on access, suggesting that improving timely care-seeking will require not only high-quality ED management but also interventions that reduce anticipated stigma, clarify escalation thresholds and make acute-care pathways more predictable and accessible.

An important observation was the consistency of findings across the USA, Canada and England. Despite differences in healthcare organisation and funding models, studies from all three countries identified similar barriers to timely care-seeking, particularly anticipated stigma, concerns regarding pain management and low trust in acute-care services. Given that SCD disproportionately affects people from minority ethnic backgrounds in these countries, these findings should also be considered within the broader context of documented racial and ethnic inequities in healthcare access, pain assessment and treatment. This consistency may suggest that some determinants of care-seeking go beyond specific healthcare systems. However, all included studies were conducted in high-income countries, limiting the transferability of findings to low- and middle-income settings where healthcare access, service organisation and sociocultural factors may differ substantially.

Implications of the results

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A central finding of this review is that many adults with SCD anticipate inequitable and suboptimal treatment in urgent care settings. Experiences and expectations of stigma, disbelief and inadequate pain management were consistently linked to delayed or avoided presentation. These findings suggest that negative care experiences and concerns about the quality and consistency of acute-care management shape help-seeking behaviour. Inadequate pain management may reflect perceived unfairness in care but may also arise from variability in clinician familiarity with SCD pain management protocols and broader organisational factors affecting care delivery. These findings raise important concerns about the quality and consistency of care delivered in emergency settings and are consistent with wider evidence of disparities in ED pain management for SCD.

Improving timely care-seeking will therefore require not only protocol-based management of VOC episodes but also efforts to reduce stigma in emergency care, improve clinician familiarity with SCD pain management protocols and ensure that acute-care pathways are experienced as consistent and trustworthy by patients. Future work should evaluate interventions aimed at improving trust between patients and providers, reducing stigma and enhancing clarity of care pathways to determine their impact on timely care-seeking and clinical outcomes.

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Table 1. Characteristics of included studies examining factors influencing urgent care-seeking during vaso-occlusive crises in individuals with sickle cell disease (n = 12)[18–29]

Study (author, year)	Country	Study design	Population	Factors	Key findings
Abdallah *et al.* 2020	USA	Cross-sectional study with multivariable logistic regression	267 adults* with SCD	Stigma experiences, pain episode frequency, health care satisfaction, prior ED visits	67% reported delaying ED care. Delay was associated with higher stigma (OR 1.09) and lower healthcare satisfaction (OR 0.74).
Binding *et al.* 2019	Canada	Before and after study of an AACU with a historical ED comparison and outpatient barriers survey	21 AACU visits for 12 unique patients and outpatient survey n = 63 adults	Barriers to using AACU pathway inc. service awareness and travel distance	Lack of information about the AACU (49.2%) and travel distance (34.9%) were the most commonly reported barriers to AACU use.
Crego *et al.* 2021	USA	Mixed-methods study with survey, interviews and focus groups	Adolescents and adults with SCD (16 to 66 years) Qualitative n = 14. Survey n = 51. Adult sample size not reported separately.**	Patient-reported ED barriers and facilitators inc. prior ED experiences, stigma and drug-seeking perceptions	60% avoided the ED due to prior negative experiences. Among those delaying care (n = 33), 60.6% identified prior ED experiences as an important influence.
Crusto *et al.* 2025	USA	Qualitative study that used focus groups and grounded theory analysis	18 adults with SCD (aged 20–68)	Perceived discrimination, stigma, and healthcare processes influencing care experiences	Participants described discrimination and stereotyping as “drug-seeking” and some reported delaying or not going to the ED to avoid mistreatment.

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Study (author, year)	Country	Study design	Population	Factors	Key findings
Durgam *et al.* 2023	Canada	Qualitative study using virtual semi-structured interviews and thematic analysis	11 adults with SCD; study also included 6 adolescent-caregiver dyads (total n = 23)	Patient-reported institutional and individual factors shaping care-seeking during VOC e.g., waiting time, presence/adherence to protocols, empathy vs racial bias, ability to self-advocate, competing responsibilities. **	Among adults, 82% identified stressors such as waiting time and stigma from hospital staff as important when deciding where to seek care during a pain crisis and the lack of care protocols and experiences of racial stigma were described as discouraging ER care-seeking.
Ibiloye *et al.* 2025	USA	National web-based cross-sectional survey that used hierarchical linear regression based on the Theory of Planned Behaviour	114 adults with SCD who had visited the ED for pain crises in the past 12 months were included in analysis from 259 responses	Attitude toward ED use and prior ED utilisation as well as stigma and prior ED experiences added to the model	Willingness to use the ED was positively associated with attitude and frequency of prior ED visits. Stigma and prior ED experiences did not significantly improve the model and were not significant predictors.
Jenerette *et al.* 2014	USA	Mixed-methods study that collected quantitative survey data and analysed open ended responses using content analysis	69 young adults with SCD (aged 18–35)	Factors influencing care-seeking and delays during SCD pain crisis e.g., home management, past ED experiences, avoiding admission.	88% reported waiting until pain averaged 8.7/10 before seeking care. The common reasons for delay included trying to manage pain at home (77%) and avoiding the ED because of past treatment (55.7%).

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Study (author, year)	Country	Study design	Population	Factors	Key findings
Kanter *et al.* 2020	USA	Multi-site survey study conducted across seven Sickle Cell Disease Implementation Consortium (SCDIC) sites	Adolescents and adults with SCD, aged 15–50 (N=440; age analysed as <19, 19–30, 31–50); Adult sample size not reported separately.**	Patient perceptions of ED care quality and related experiences including influence of prior bad ED experiences.	67% (254/379) reported they had delayed or avoided going to the ED when they thought they needed care in the past 12 months and 52% reported that bad ED experiences influenced their decisions to avoid seeking care.
Linton *et al.* 2020	USA	Cross-sectional needs assessment survey of patients and ED providers	Patients with SCD: 516 total respondents where adolescents n=93; adults n=354; age missing n=69). Adult-only n is available (n=354), but results are reported for the combined patient sample unless specified.**	Patient-reported ED experience barriers e.g., timeliness and wait times, being believed or cared for, unpleasant ED experiences and access barriers such as insurance issues related to delaying and avoiding ED use.	66% of patient respondents reported delaying or avoiding going to the ED in the last 12 months; among those with ED use, delay/avoidance was 69.6% vs 47.4% in non-ED users. 54.3% reported not getting timely care. 46% thought that doctors did not care about them. Overall, 48.6% of patients were “never” or “sometimes” satisfied with their care.
Renedo *et al.* 2019	England	Longitudinal qualitative study with 80 interviews with inductive analysis	48 young people with SCD aged 13–21. The adult-only is not fully separable as the paper reports 17 one-off interviews with 19–21-year-olds, but 18-year-olds are included within the 16–18 group.**	Experiences of unplanned care A&E and inpatient wards during painful episodes in transition to adult services.	Participants reported delays to pain relief, not being listened to and “not being heard,” and adult wards as unwelcoming. They described trying to avoid hospital admission by self-managing at home and using unplanned care as a last resort.

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Study (author, year)	Country	Study design	Population	Factors	Key findings
Smith *et al.* 2017	USA	Prospective cross-sectional mixed-methods descriptive study using structured and open-ended interviews	Adults with SCD presenting to ED for VOE; 147 interviews conducted over 14 months with some patients interviewed more than once.	Social and behavioural and access barriers relevant to seeking care e.g., transport and scheduling barriers, prescription access, insurance issues, perceived stigma in ED.	In 27% of interviews, patients reported insurance coverage issues. Qualitative comments described ED stigma e.g., being treated as “drug seeker” and long waits as discouraging ED use.
Young *et al.* 2020	USA	Qualitative photovoice study with group dialogue	8 adults with SCD (Black and aged 26–56) with at least one ED visit for VOC in the past 2 years.	Perceptions and experiences shaping ED care-seeking e.g., stigma, communication, fear and lack of control.	Participants identified ED avoidance as a core theme and described delaying ED visits because of stigma e.g., fear of being perceived as drug-seeking as well as poor communication.

* Adults are defined as aged 18 years and over.
** Mixed-age samples included adults, but adult-specific findings were not consistently reported separately
Abbreviations: SCD = Sickle Cell Disease; ED = Emergency Department; AACU = Ambulatory Acute Care Unit; ER = Emergency Room; VOE = Vaso-occlusive Events; VOC = Vaso-occlusive Crisis; A&E = Accident and Emergency; OR = Odds Ratio

Table 1. Characteristics of included studies examining factors influencing urgent care-seeking during vaso-occlusive crises in individuals with sickle cell disease (n = 12)

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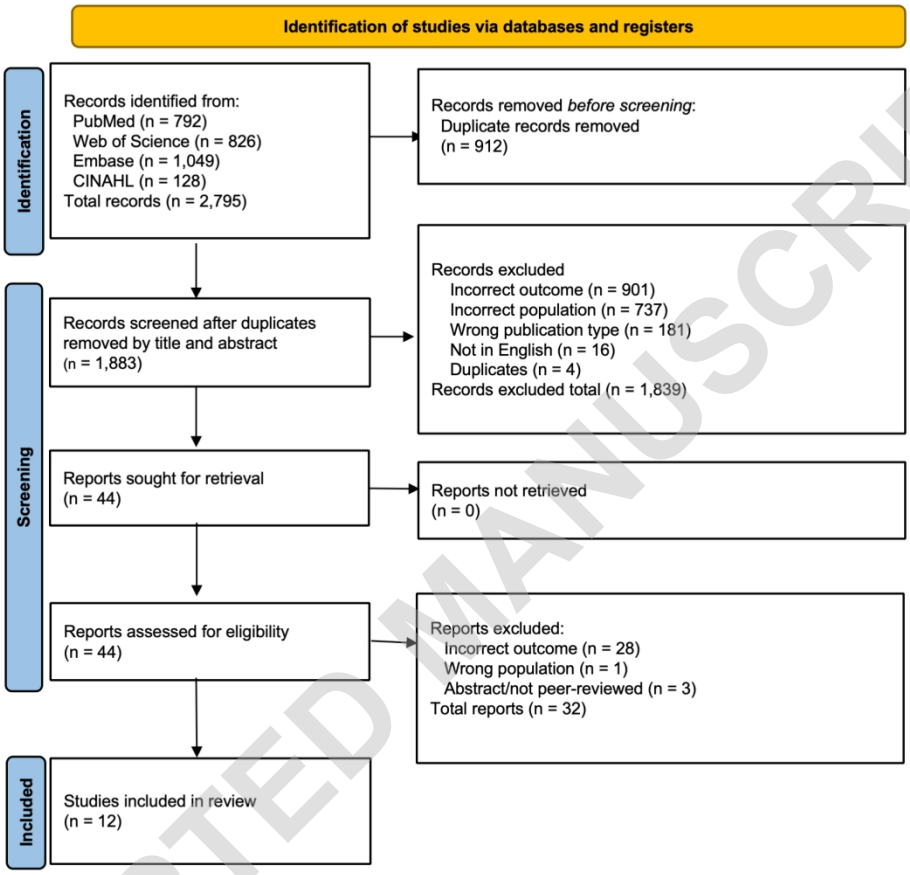


Figure 1. PRISMA flow diagram of study selection for the systematic review of factors influencing urgent care-seeking during vaso-occlusive crises in adults with sickle cell disease.

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