Literature Review: Exploring Stigma and Pain Outcomes Among Individuals Living with Sickle Cell Disease

Lateasha B. Grant-Lennon

Department of Social Work, North Carolina Agricultural & Technical State University

SOWK 853: Quantitative Methods in Social Work

Dr. Mashooq Salehin

April 14, 2026

Introduction

Sickle Cell Disease (SCD) is a hereditary blood disorder first identified in the United States by James Bryan Herrick in 1910 (NHLBI, 2014). It is hypothesized that the sickle gene originated and mutated in African regions, where the trait provided a protective advantage against malaria in tropical environments. While this evolutionary adaptation offered survival benefits in Africa, it has since manifested as a chronic and debilitating disease affecting millions worldwide. According to the National Heart, Lung, and Blood Institute, SCD affects more than eight million people globally, with Nigeria having the highest prevalence of individuals living with the disease (NHLBI, 2014). Sickle Cell Disease disproportionately affects individuals of African, Caribbean, Middle Eastern, Mediterranean, and Indian descent, reflecting its geographic and genetic origins.

In the United States, approximately 100,000 individuals are living with SCD, with the disease largely concentrated among historically marginalized populations. The burden of SCD is not solely biological; it is deeply intertwined with social, structural, and systemic inequities. SCD is common among historically marginalized populations in the U.S. and is associated with significant health disparities, including a median life expectancy in the fourth decade, at least 20 years shorter than the median life expectancy of African Americans in the United States (Centers for Disease Control and Prevention [CDC], 2024). Despite advances in medical treatment and increased awareness of the disease, individuals with SCD continue to experience significant disparities in healthcare access, quality of care, and health outcomes.

Individuals with SCD suffer from a wide range of complications, including strokes, kidney disease, acute chest syndrome, and long-term disability. However, the defining characteristic of the disease is the presence of recurrent, unpredictable pain episodes, commonly

referred to as Vaso-occlusive crises. These episodes often require immediate pharmacological intervention to prevent further complications, including organ damage and death. Healthcare providers widely recognize that timely and aggressive pain management is the standard of care. Historically, these pain episodes have been treated with opioid medications. However, the management of pain in SCD has become increasingly complex in the context of the opioid epidemic, which has reshaped prescribing practices and heightened provider scrutiny of opioid use.

This shift has disproportionately impacted individuals with SCD, many of whom report that their pain is not believed, that they are mistreated, and that they are frequently labeled as drug-seeking when seeking care in emergency department (ED) settings. According to Alao, Westmoreland, and Jindal (2003), there is no scientific evidence to support the claim that individuals with SCD are at increased risk of opioid dependence when their pain is appropriately managed. Despite this, stigma surrounding opioid use and racialized assumptions about pain and addiction continue to influence clinical decision-making.

It is hypothesized that the mistreatment of individuals with SCD is attributable to both a lack of provider expertise and the presence of implicit and explicit bias within healthcare systems. Healthcare providers' preconceived notions about specific diagnoses or patient populations can significantly influence the quality of care delivered. These biases are often unrecognized yet deeply embedded within clinical practice, contributing to disparities in treatment and patient outcomes. This literature review aims to bring awareness to the persistent and cyclical nature of healthcare bias experienced by individuals living with Sickle Cell Disease and how this bias affects pain outcomes.

Critical Race Theorist Kimberlé Crenshaw (1989) advanced the concept of interconnected social identities through the coining of the term “intersectionality,” providing a critical framework for understanding how multiple forms of oppression operate simultaneously. Issues of power, positionality, and representation are central to examining disparities in Sickle Cell Disease care, particularly within clinical settings where decision-making authority is largely concentrated among healthcare providers. Power is enacted through clinical gatekeeping, as providers control access to pain management, assess the credibility of patient-reported symptoms, and ultimately determine treatment pathways. Individuals with SCD who are predominantly from historically marginalized racial groups are often positioned at a disadvantage within these interactions, where their lived experiences may be questioned, minimized, or dismissed. Positionality further shapes these dynamics, as providers’ social identities, professional training, and implicit biases influence how they interpret and respond to expressions of pain. Conversely, patients’ positionality as individuals living with a stigmatized and largely invisible illness increases their vulnerability to misrepresentation and inadequate care. Representation within the literature has also been limited, frequently failing to center patient perspectives or fully capture the complexity of their experiences. Guided by an intersectional framework, this review examines how overlapping identities, particularly race, socioeconomic status and chronic illness, intersect to produce compounded forms of disadvantage in healthcare contexts. Methodologically, the studies included in this review primarily employ quantitative approaches, including survey designs, stigma scales, and patient-reported outcome measures to assess perceived discrimination, provider bias, and healthcare experiences. Additionally, several studies utilize comparative analyses to explore the relationships between stigma and health

outcomes, offering deeper insight into how structural and interpersonal factors converge to shape stigma and disparities in SCD pain management.

This literature review examines how stigma influences pain management outcomes among individuals living with Sickle Cell Disease. Specifically, it addresses the following research question: *How does perceived stigma affect pain management and healthcare experiences among individuals with SCD in clinical settings?* By synthesizing quantitative findings, this review highlights key themes related to stigma, provider bias, and systemic inequities that contribute to disparities in care.

Overview of Sickle Cell Disease and Pain Management

The hallmark symptom of Sickle Cell Disease is recurrent, unpredictable pain which requires providers to rely heavily on patient self-report, as pain cannot be objectively measured. This reliance creates a unique vulnerability, as patient credibility becomes central to clinical decision-making. A substantial body of literature identifies stigma as a critical factor influencing pain management outcomes in this population. Stigma, defined as the co-occurrence of labeling, stereotyping, and discrimination (Sartorius, 2006), has been operationalized in quantitative research through measures of perceived discrimination, provider bias, and patient-reported healthcare experiences. Individuals with SCD consistently report higher levels of perceived stigma compared to those with other chronic conditions, and these experiences are strongly associated with delayed care-seeking, reduced adherence to treatment, and poorer overall health outcomes.

Sickle Cell Disease is often described as an “invisible illness,” as its most debilitating symptom pain, lacks visible or measurable indicators. Unlike other conditions that can be

confirmed through imaging or laboratory values, SCD pain relies entirely on patient self-report. This reliance introduces subjectivity into clinical decision-making, making the patient-provider relationship a critical determinant of care quality. The variability of SCD further complicates treatment. Pain episodes differ in frequency, intensity, and duration across individuals, necessitating personalized approaches to care. Research consistently demonstrates that standardized, one-size-fits-all treatment models are insufficient for managing SCD pain effectively. In response, individualized pain management plans have been developed as a strategy to improve care consistency and patient outcomes. These plans typically include tailored medication regimens, dosing schedules, and preferred interventions based on the patient's history and response to treatment.

Evidence suggests that adherence to individualized pain plans improves timeliness of care, reduces hospital admissions, and enhances patient satisfaction. Patients who receive care aligned with their established pain plans are more likely to report feeling heard, respected, and effectively treated. However, despite their demonstrated effectiveness, adherence to these plans remains inconsistent, particularly in emergency department settings. Providers may deviate from established protocols due to time constraints, lack of familiarity with SCD, or skepticism regarding patient-reported pain. These inconsistencies contribute to delayed treatment, inadequate pain control, and increased patient distress. The gap between evidence-based recommendations and clinical practice underscores the need to examine underlying factors influencing provider behavior, including stigma and bias.

Stigma and Healthcare Disparities

A substantial body of literature identifies stigma as a central factor contributing to disparities in SCD care. Stigma is often conceptualized as a social process involving labeling,

stereotyping, and discrimination, resulting in the devaluation of individuals based on a particular characteristic or condition (Sartorius, 2006). In the context of SCD, stigma operates at multiple levels, including interpersonal interactions, institutional practices, and broader societal attitudes.

Individuals with SCD report significantly higher levels of perceived stigma compared to individuals with other chronic illnesses. These experiences include being doubted, dismissed, or treated with suspicion when seeking care. Importantly, stigma in SCD is intersectional, shaped by both disease status and racial identity. In the United States, where SCD predominantly affects Black individuals, racial bias compounds disease-related stigma, creating a layered and deeply entrenched system of disadvantage.

Alvarez et al. (2019) found that individuals with SCD frequently report discriminatory treatment and limited access to quality care. These findings are supported by broader analyses of healthcare funding, which reveal significant disparities in resource allocation. Diseases affecting predominantly White populations, such as cystic fibrosis, receive disproportionately higher levels of research funding relative to disease burden. As a marginalized diagnosis, Sickle Cell Disease receive less awareness and less funding is allocated for research and resources, in comparison to the several millions of dollars allocated to the 40,000 persons in the U.S. living with Cystic Fibrosis (Cystic Fibrosis Foundation, 2025). These disparities have far-reaching implications, influencing provider education, availability of specialized care, and the development of evidence-based interventions.

Weiss, Ramakrishna, and Somma (2006) define health-related stigma as a form of devaluation or social disqualification based on a health condition. In the case of SCD, this stigma is often evident during acute pain crises, when individuals are most vulnerable and in need of

immediate care. Delays in treatment, denial of medication, and dismissive attitudes from providers are not merely clinical oversights, they are manifestations of systemic stigma.

Research consistently demonstrates that individuals with SCD experience longer wait times in emergency department settings compared to patients with other conditions (Haywood et al., 2013). Glassberg et al. (2013) further found that adherence to pain management guidelines is inconsistent, contributing to suboptimal care. These patterns reflect systemic inequities rather than isolated incidents, highlighting the pervasive influence of stigma on healthcare delivery.

Provider Bias and Communication

Provider attitudes and communication behaviors play a critical role in shaping patient experiences and outcomes. Individuals with SCD frequently report negative interactions with healthcare providers, including not being believed, being interrupted, and being excluded from decision-making processes. These experiences are often rooted in implicit bias, which can influence provider perceptions and behaviors without conscious awareness.

Anderson et al. (2023) found that higher levels of provider bias are significantly associated with lower adherence to clinical guidelines and poorer patient outcomes. This suggests that bias not only affects interpersonal interactions but also directly impacts the quality of care delivered. Similarly, Jacob (2001) identified that patient requests for specific pain medications are often misinterpreted as drug-seeking behavior rather than informed self-advocacy. This misinterpretation has significant consequences. Patients who are labeled as drug-seeking may experience delays in treatment, receive inadequate pain relief, or be denied care altogether. Jenerette and Brewer (2010) further explored the concept of patient credibility, noting that individuals with SCD are often required to prove the legitimacy of their pain. This additional

burden creates a barrier to care and reinforces feelings of mistrust and marginalization. Importantly, research indicates that disparities persist even when communication quality is controlled, suggesting that implicit bias, rather than patient behavior is a primary driver of inequities. Addressing these biases requires intentional efforts, including provider education, self-reflection, and institutional accountability.

Systemic Inequities in Pain Management

Despite the availability of evidence-based guidelines, adherence to SCD pain management protocols remains inconsistent across healthcare settings. Glassberg et al. (2013) reported that many emergency department providers deviate from recommended practices, often due to time constraints, lack of training, or implicit bias. These deviations result in increased pain severity, longer hospital stays, and decreased patient satisfaction.

Continuity of care has emerged as a key factor in mitigating these disparities. Individuals with established relationships with primary care providers or SCD specialists report lower levels of perceived stigma and improved healthcare experiences. Integrated care models that emphasize collaboration and continuity have shown promise in improving outcomes for individuals with SCD. However, access to such models remains limited, particularly for individuals in underserved communities. Addressing systemic inequities requires not only changes in clinical practice but also broader structural reforms, including increased funding, improved access to specialized care, and policy-level interventions.

Implications for Research and Practice

The literature highlights the urgent need for targeted interventions to address stigma and improve pain management outcomes for individuals with SCD. Provider education and implicit

bias training are critical components of this effort, as they can help increase awareness and promote more equitable care practices. Standardized pain management protocols, when consistently implemented, have the potential to reduce variability in care and improve patient outcomes. Additionally, increasing investment in SCD research and expanding access to specialized care can help address systemic disparities. Future research should focus on developing and evaluating interventions aimed at reducing stigma and improving provider adherence to clinical guidelines. Longitudinal studies are particularly needed to examine how stigma influences healthcare utilization and outcomes over time.

Conclusion

In summary, the literature makes it clear that stigma is not a minor issue; it is a powerful, shaping force that directly influences how pain is perceived, assessed, and treated for individuals living with Sickle Cell Disease. Behind every clinical interaction is a person navigating not only severe, often unpredictable pain, but also the burden of being doubted, dismissed, or misunderstood. When examined through a critical race and intersectionality lens, these experiences are not random they are structured by overlapping systems of inequality, including race, class, gender, and health status, that disproportionately impact Black patients and others with marginalized identities. Provider bias, inconsistent adherence to evidence-based guidelines, and deeply rooted systemic inequities do more than create gaps in care; they erode trust, delay relief, and, in some cases, cost lives, particularly in high-stakes environments such as emergency departments.

This topic matters profoundly for social work research, policy, and practice because it sits at the intersection of health equity, structural injustice, and human dignity. Social workers are uniquely positioned to address these disparities by advancing research that centers lived

experience, advocating for equitable pain management policies, and promoting anti-racist, trauma-informed care practices within interdisciplinary teams. A commitment to equity and inclusion requires moving beyond surface-level interventions to critically examine how institutional practices and knowledge production in healthcare may perpetuate harm. It also demands that social work scholarship uphold its ethical responsibility to challenge injustice, amplify marginalized voices, and translate evidence into meaningful systemic change.

While interventions such as individualized pain management plans and improved continuity of care offer meaningful progress, they cannot reach their full potential without a deliberate and sustained effort to confront stigma at every level of the healthcare system. This work requires more than clinical competence; it demands humility, active listening, and a willingness to recognize patients as experts of their own pain. To care for individuals with Sickle Cell Disease is to honor their resilience while refusing to normalize their suffering.

Ultimately, improving outcomes is not solely about refining protocols; it is about restoring dignity. It calls on healthcare professionals and especially social workers to move beyond assumptions, challenge inequities, and engage with compassion that is both intentional and actionable. Every encounter is an opportunity to practice ethical, equity-driven care, ensuring that no patient’s pain is minimized or ignored, and that justice remains central to both scholarship and practice.

References

Alao, A. O., Westmoreland, N., & Jindal, S. (2003). Drug addiction in sickle cell disease: Case report. *International Journal of Psychiatry in Medicine, 33*(1), 97–101. https://doi.org/10.2190/7XMD-L45D-47DH-7MEC.

Alvarez, O. A., et al. (2019). Patient perception on health care delivery for sickle cell disease and opportunities for quality improvement. *Blood Advances*.

Anderson, D., Lien, K., Agwu, C., Ang, P. S., & Abou Baker, N. (2023). The bias of medicine in sickle cell disease. *Journal of General Internal Medicine, 38*, 3247–3251. https://doi.org/10.1007/s11606-023-08392-0.

Centers for Disease Control and Prevention. (2024). Sickle cell disease data and statistics. https://www.cdc.gov.

Crenshaw, K. (1989). Demarginalizing the intersection of race and sex: A Black feminist critique of antidiscrimination doctrine, feminist theory, and antiracist politics. *University of Chicago Legal Forum*, 1, 139-167.

Cystic Fibrosis Foundation. (n.d.). *About Cystic Fibrosis*. Retrieved March 30, 2026, from https://www.cff.org/intro-cf/about-cystic-fibrosis.

Glassberg, J. A., Tanabe, P., Chow, A., Harper, K., Haywood, C., DeBaun, M. R., & Richardson, L. D. (2013). Emergency provider analgesic practices and attitudes toward patients with

sickle cell disease. *Annals of Emergency Medicine, 62*(4), 291–302.

Haywood, C., Jr., Tanabe, P., Naik, R., Beach, M. C., & Lanzkron, S. (2013). The impact of race and disease on sickle cell patient wait times in the emergency department. *American Journal of Emergency Medicine, 31*(4), 651–656.

Jacob, E. (2001). Pain management in sickle cell disease. *Pain Management Nursing, 2*(4), 121–131.

Jenerette, C. M., & Brewer, C. (2010). Health-related stigma in young adults with sickle cell disease. *Journal of the National Medical Association, 102*(11), 1050–1055.

National Heart, Lung, and Blood Institute. (2014). *Evidence-based management of sickle cell disease: Expert panel report*. U.S. Department of Health and Human Services.

Sartorius, N. (2006). Lessons from a 10-year global programme against stigma and discrimination because of an illness. *Psychology, Health & Medicine, 11*(3), 383–388.

Weiss, M. G., Ramakrishna, J., & Somma, D. (2006). Health-related stigma: Rethinking concepts and interventions. *Psychology, Health & Medicine, 11*(3), 277–287.

What Is Sickle Cell Disease (SCD)? [(accessed on 28 March 2026)]; Available online: https://www.cdc.gov/ncbddd/sicklecell/features/what-is-scd.html.