Qualifying Portfolio: How does healthcare-related stigma influence pain management and healthcare experiences among adults living with Sickle Cell Disease?

Lateasha B. Grant-Lennon

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

July 22, 2026

Research Statement

The social problem I wish to address through my dissertation is the persistent stigma and healthcare bias experienced by individuals living with Sickle Cell Disease (SCD), particularly during pain management encounters. 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. Individuals with SCD are frequently labeled as drug-seeking, have their pain dismissed, experience delayed treatment, and receive inadequate pain management in healthcare settings. These experiences contribute to mistrust of healthcare providers, avoidance of necessary care, poorer health outcomes, and reduced quality of life. On page 2 of my Literature Review The CDC (2024) notes that SCD's burden extends beyond biology to social, structural, and systemic inequities and adds how it disproportionately affects historically marginalized U.S. populations, contributing to a median life expectancy in the fourth decade at least 20 years shorter than that of African Americans overall. Because SCD disproportionately affects individuals of African descent, these disparities represent a significant social justice and health equity issue that warrants further investigation.

Gap in the Literature

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. Existing research has documented stigma, provider bias, and disparities in pain management among individuals with SCD. While quantitative studies have demonstrated that these disparities exist, they provide limited insight into how individuals experience and interpret healthcare-related stigma. At the same time, there is a need for additional research that amplifies the voices of individuals living with SCD and examines how stigma influences pain management, healthcare decision-making, trust in providers, and healthcare utilization. Anderson et al. (2023) found that higher levels of provider bias are significantly associated with lower adherence to clinical guidelines and poorer patient outcomes. Expanding this body of knowledge can inform more equitable, patient-centered care.

Overarching Research Question

How does healthcare-related stigma influence pain management and healthcare experiences among adults living with Sickle Cell Disease?

Secondary Research Questions

- How do experiences of stigma influence pain management?
- How do individuals with SCD perceive their interactions with healthcare providers?
- How does healthcare-related stigma affect decisions to seek or avoid care?

Type of Study

At this stage of my doctoral journey, I have not definitively decided whether my dissertation will use a qualitative or quantitative research approach because I recognize the unique strengths that each paradigm offers. Through my coursework, I have developed an appreciation for the strengths of both methodologies. Quantitative methods are valuable for

identifying patterns, measuring the extent of healthcare stigma, and examining relationships between stigma and health outcomes. Qualitative methods offer the opportunity to explore participants lived experiences and provide a deeper understanding of how stigma shapes healthcare interactions and pain management. As I continue to refine my research agenda, I will determine which approach or potentially a mixed-methods design best addresses my research questions and captures the experiences of individuals living with Sickle Cell Disease. Although I have not yet decided whether a qualitative or quantitative approach will best address my research questions, I am particularly drawn to qualitative methods that center the voices of individuals living with Sickle Cell Disease. Specifically, I am interested in using phenomenological or narrative approaches, supported by thematic analysis, to better understand participants lived experiences and the meaning they assign to those experiences. As I further develop my research questions through coursework and the literature, I hope to determine which approach will best address the phenomenon I seek to understand. Regardless of the methodology ultimately selected, my research will be guided by Intersectionality Theory, Critical Race Theory, Conflict Theory, and Ecological Systems Theory, with the goal of generating knowledge that informs equitable, patient-centered practice and policy for individuals living with Sickle Cell Disease.

Student Learning Outcome: Written Communication

Throughout my doctoral studies, I have learned that culturally responsive research requires researchers to value participants as experts of their own experiences and to promote collaboration, equity, and social justice at the micro, mezzo, and macro levels. These principles are central to my proposed research on healthcare-related stigma and pain management among adults living with Sickle Cell Disease (SCD).

At the micro level, culturally responsive research begins with listening rather than making

assumptions. Every individual with SCD experiences stigma differently, so participants must have the opportunity to share their healthcare experiences in their own words. In my study, I would use either a survey, scale or semi-structured interviews to understand how participants perceive stigma, navigate pain management, and make decisions about seeking care. Please see a scale example on page 9, of the assignment Sickle Cell Healthcare Racial Stigma Scale (SCHRSS): Instrument for Social Work Research. As a social worker and an individual living with SCD, I recognize the importance of reflexivity and ensuring that participants' voices—not my own experiences guide the findings.

At the mezzo level, I have learned that meaningful research requires collaboration with community organizations and healthcare providers. Hospitals and community-based organizations (CBOs) both play essential roles in supporting individuals with SCD, but they are most effective when they work together. Partnering with organizations such as Piedmont Health Services and Sickle Cell Agency and Atrium Levine Cancer Institute would strengthen recruitment, ensure the research reflects community priorities, and help translate findings into practice. Most importantly, without participants who are willing to share their experiences, neither community nor healthcare organizations nor researchers can effectively improve care.

At the macro level, culturally responsive research should inform policy and systems change. State agencies can use findings from participants and community and health organizations to fund advocacy efforts, evaluate effective interventions, and develop policies that reduce healthcare inequities. Research findings can also be shared nationally to improve provider education, promote evidence-based practices, and advance equitable pain management for individuals living with SCD.

Overall, I have learned that culturally responsive research is built on listening, partnership, and action. By centering participants lived experiences, collaborating with community and health organizations, and using research to inform policy, researchers can generate knowledge that not only advances science but also improves the lives of individuals and communities.

Student Learning Outcome: Analyze Models

Throughout my doctoral studies, I have learned that different research paradigms are designed to answer different types of research questions. Two models that are particularly relevant to my emerging research interests on healthcare stigma, disease management and intimate relationships among individuals living with Sickle Cell Disease (SCD) are the Positivist and Constructivist (Interpretivist) models.

The Positivist Model is grounded in the epistemological stance that reality exists independently of the researcher and can be objectively measured through scientific inquiry. This model typically employs quantitative research designs such as surveys, correlational studies, cross-sectional studies, and experimental or quasi-experimental methods. If I were to use a positivist approach, I could examine relationships between variables, such as whether experiences of healthcare stigma or unhealthy intimate relationships are associated with disease management outcomes, healthcare utilization, or quality of life among adults living with SCD. The primary advantage of this model is its ability to produce measurable, generalizable findings that can inform policy, intervention development, and evidence-based practice. However, its primary limitation is that it may not fully capture the complexity of individuals lived experiences or the meaning they assign to those experiences.

The Constructivist (Interpretivist) Model is based on the epistemological stance that reality is socially constructed and shaped by individuals' experiences, relationships, and cultural contexts. Researchers using this paradigm commonly employ qualitative methods such as phenomenology, narrative inquiry, case studies, or grounded theory, relying on interviews, focus groups, and thematic analysis to understand participants' perspectives. A constructivist approach would allow me to explore how adults living with SCD experience healthcare stigma, navigate intimate relationships, and make decisions related to disease management. The greatest strength of this model is its ability to generate rich, in-depth understanding of participants lived experiences and the social processes that influence health behaviors. A limitation is that findings are generally based on smaller, context-specific samples and therefore may not be broadly generalizable.

Both models offer valuable but distinct contributions to research on Sickle Cell Disease. The positivist model is well suited for determining whether relationships exist among measurable variables and estimating the magnitude of those relationships across larger populations. In contrast, the constructivist model provides a deeper understanding of how individuals experience and interpret those relationships within the context of their everyday lives. At this point, I remain open to either research paradigm because both align with different aspects of my research interests. A quantitative approach could provide evidence regarding the extent to which stigma or relationship factors influence health outcomes, while a qualitative approach could illuminate the lived experiences behind those associations. As I continue developing my dissertation topic and reviewing the literature, I will determine which model best answers my overarching research question and aligns with the type of knowledge I hope to contribute to the field of social work and Sickle Cell Disease research.

Student Learning Outcome: Integrate Social Work Ethics

Alvarez et al. (2019) found that individuals with SCD frequently report discriminatory treatment and limited access to quality care. My research on healthcare-related stigma and pain management among individuals living with Sickle Cell Disease (SCD) is grounded in several NASW (2021) ethical principles, particularly Social Justice, Dignity and Worth of the Person, and the Importance of Human Relationship**s** which aim to improve the quality of care.

The principle of Social Justice is central to my research because it seeks to address healthcare inequities experienced by individuals with SCD, a population that is predominantly Black and has historically faced bias, inadequate pain management, and discrimination. By centering participants lived experiences, I hope to generate evidence that informs advocacy, improves clinical practice, and supports policy changes that promote equitable healthcare. One challenge is ensuring the research leads to meaningful systems change rather than simply documenting disparities.

The principle of Dignity and Worth of the Person guides my commitment to valuing participants as experts of their own experiences. Rather than imposing assumptions, my research will amplify their voices and acknowledge the unique ways stigma influences healthcare decisions and pain management. A challenge is balancing my dual role as both a social worker and an individual living with SCD. While this perspective strengthens cultural understanding, I must practice reflexivity throughout the research process to ensure participants' experiences; not my own shape the findings.

Finally, the Importance of Human Relationships underscores the need to build authentic partnerships with participants, healthcare providers, and community-based organizations.

Meaningful collaboration increases trust, improves the relevance of the research, and helps translate findings into practice. A challenge is maintaining these collaborative relationships while preserving the independence and rigor of the research process. Researchers must balance input with maintaining objectivity by ensuring transparency, clear roles, and adherence to ethical research standards.

Overall, I believe ethical research extends beyond protecting participants. It requires using research to elevate marginalized voices, challenge systemic inequities, and produce knowledge that leads to meaningful improvements in the lives of individuals living with Sickle Cell Disease. This commitment reflects the NASW's remaining core values of service by advancing research that benefits underserved communities, integrity by conducting research with honesty, transparency, and accountability, and competence by applying rigorous, culturally responsive methods that contribute meaningful and trustworthy evidence to the social work profession.

Student Learning Outcome: Participate in Research

Throughout my doctoral program, I have strengthened my research skills through coursework, graduate assistantship experiences, attending research seminars and scholarly writing. I have learned to critically evaluate the literature, identify gaps in knowledge, develop research questions, and select methods that best address complex social work issues. Please see an example of research questions on page 2, of the assignment Interview Questions: How intimate partner relationships influence health outcomes among individuals living with Sickle Cell Disease.

Beyond the classroom, I expanded these skills by transcribing two qualitative interviews for Dr. Teixeira-Poit's research and contributed to a literature review for Dr. Dinnerson's research. These experiences deepened my understanding of qualitative data collection, thematic analysis, and the importance of grounding research in existing evidence. They also reinforced the value of methodological rigor, reflexivity, and culturally responsive research.

As my research interests have evolved, I have become increasingly interested in methods that allow me to explore healthcare-related stigma among individuals living with Sickle Cell Disease (SCD). I have developed skills in creating an interview guide and survey, designing interview protocols, integrating theoretical frameworks, and planning thematic analyses that center participants lived experiences. My coursework has prepared me to design research that is both scientifically rigorous and responsive to the needs of historically marginalized communities.

These experiences have equipped me to generate knowledge that can improve social work practice and inform health policy. My goal is to produce research that amplifies the voices of individuals living with SCD, informs equitable and patient-centered care, and contributes to reducing healthcare disparities. I also look forward to sharing my emerging research agenda at the upcoming Sickle Cell Disease Association of America's Annual Conference, where I hope to contribute to ongoing conversations about improving outcomes for individuals living with SCD.

Student Learning Outcome: Understanding and Application of Theory

The theories most relevant to my research are Intersectionality Theory, Critical Race Theory (CRT), Conflict Theory, and Ecological Systems Theory. Together, these frameworks guide my understanding of how healthcare stigma influences pain management and healthcare experiences among individuals living with Sickle Cell Disease (SCD).

Intersectionality Theory (Crenshaw, 1989) and Critical Race Theory CRT (Delgado & Stefanic, 2017) are central to my research. Intersectionality; helps me examine how race, chronic illness, socioeconomic status, and other identities interact to shape experiences of stigma and healthcare. CRT provides a framework for understanding how structural racism and power influence provider bias, pain management, and access to quality care for a disease that disproportionately affects Black individuals.

Conflict Theory (Engles & Marx, 1848/2015) complements these perspectives by examining the power imbalance between healthcare providers and patients, particularly when individuals with SCD must justify the legitimacy of their pain. Ecological Systems Theory (Bronfenbrenner, 2005) broadens this lens by recognizing that healthcare experiences are shaped by multiple systems, including families, communities, healthcare organizations, and public policy.

These theories provide a strong foundation for examining how healthcare stigma influences the experiences of individuals living with Sickle Cell Disease. As I continue to refine my research interests, I am exploring the epistemological stance and research methods that will best address my research questions. Together, these theories will guide my future research by providing a framework for examining individual experiences within broader social and structural contexts. Ultimately, I hope my research will advance knowledge, inform social work practice and healthcare policy, and contribute to more equitable, patient centered care for individuals living with Sickle Cell Disease.

References

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.

Bronfenbrenner, U. (2005). *Making human beings human: Bioecological perspectives on human development.* Sage Publications.

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.

Delgado, R., & Stefancic, J. (2017). *Critical race theory: An introduction* (3rd ed.). New York University Press.

Engels, F., & Marx, K. (2015*). The communist manifesto.* Penguin Classics.

National Association of Social Workers. (2021). *Code of ethics-English*. National Association of Social workers. https://www.socialworkers.org/about/ethics/code-of-ethics/code-of-ethics-

English.

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.