Measuring What They Refuse to See:

Development of the Sickle Cell Healthcare Racial Stigma Scale (SCHRSS)

Instrument for Social Work Research

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I have lived with Sickle Cell Disease (SCD) my entire life, and I have spent years working inside healthcare as a social worker and case manager. These two positions; patient and practitioner has given me a clear, unfiltered view of the system: I know what it feels like to be dismissed in the emergency department, to have my pain questioned, to be labeled a drug-seeker instead of recognized as a person in crisis. I also know how rarely these realities are captured, measured, or taken seriously in formal ways. This paper introduces the Sickle Cell Healthcare Racial Stigma Scale (SCHRSS), an instrument I developed to assess how Black adults with SCD experience perceive, and resist stigma in healthcare settings. This is not abstract work. It is an effort to quantify what has shaped my life and the lives of the people I serve.

For purposes of this instrument, sickle cell healthcare racial stigma is defined as the extent to which Black adults with SCD perceive, experience the burden of, and actively resist the socially constructed devaluation of their identity as both a Black person and a chronic pain patient within healthcare systems. This definition is grounded in critical race theory and intersectionality: stigma in this context is not merely a personal perception but a structural product of racialized medicine, reinforced through provider attitudes, institutional policies, and systemic underinvestment in SCD research and treatment (Haywood et al., 2014). The construct matters for social work because SCD related stigma is directly linked to avoidance of care, mental health burden, undertreated pain, and decreased quality of life (Bulgin et al., 2018; Matthie et al., 2015). This definition extends Link and Phelan's (2001) structural stigma model by locating stigma within the specific intersection of race and chronic illness in healthcare. Unlike general medical mistrust measures, this instrument explicitly names anti-Black racism as a structural driver of stigma, consistent with a standpoint epistemology that centers the knowledge produced from lived experience (Collins, 2000).

The SCHRSS is grounded in four complementary frameworks. Link and Phelan's (2001) stigma model which conceptualizes stigma as a social process of labeling, stereotyping, status loss, and discrimination exercised through power provides the structural foundation. Major and O'Brien's (2005) identity threat framework explains the psychological and behavioral mechanisms by which stigma awareness produces vigilance, emotional exhaustion, and identity management strategies; this directly informs the psychological burden and self-protective vigilance subscales. Cross's (1991) Nigrescence Theory contributes a resistance lens, tracking how individuals move from internalized stigma toward affirming identity. Sellers et al.'s (1998) Multidimensional Model of Racial Identity (MMRI) further informs the instrument by attending to both how identity is perceived by others and how it is maintained internally. Together, these frameworks position sickle cell racial healthcare stigma as simultaneously structural, psychological, behavioral, and resistible and justify a multidimensional scale.

The SCHRSS was designed specifically for Black American adults aged 18 and older who are living with a confirmed diagnosis of Sickle Cell Disease. This specificity is intentional. SCD affects approximately 100,000 Americans, the overwhelming majority of whom are Black, and stigma in healthcare contexts for this population is shaped by the intersection of anti-Black racism and the racialized history of pain management in medicine (Haywood et al., 2014). Generic chronic illness stigma measures fail to capture this specificity. Population-specific instrumentation is both a methodological necessity and an ethical commitment.

The SCHRSS is conceptualized as multidimensional with five theoretically grounded subscales. Subscale 1: Perceived Provider Stigma (PPS), grounded in Link and Phelan (2001), measures the degree to which individuals perceive provider attitudes and behaviors as reflecting racial or disease-based stigma, including doubting pain or making race-based assumptions.

Subscale 2: Institutional Devaluation and Exclusion (IDE) measures perceived denial of equitable care and structural barriers to treatment linked to SCD and racial identity. Subscale 3: Psychological Burden of Healthcare Stigma (PBHS), grounded in Major and O'Brien (2005), captures the emotional toll of navigating stigmatizing healthcare environments. Subscale 4: Protective Vigilance and Self-Advocacy (PVSA) measures the behavioral labor of managing stigma in healthcare, such as bringing documentation and modulating self-presentation. Subscale 5: Stigma Resistance and Identity Affirmation (SRIA), grounded in Cross's (1991) internalization stage, assesses the extent to which individuals reject stigmatizing narratives and draw on cultural resources as resilience. Subscales 1–4 form a Healthcare Stigma Burden Index (HSBI); Subscale 5 functions as an independent Stigma Resistance Score (SRS).

The SCHRSS contains 20 items, four per subscale. This structure was selected to capture all theoretically specified dimensions while minimizing respondent burden, consistent with DeVellis's (2017) recommendations for pilot instruments. The dual-index design is a deliberate theoretical decision: a single global score would obscure clinically meaningful variation. Items are clear, non-reductive, and culturally responsive. Five items are reverse scored (Items 3, 7, 11, 15, 19) to reduce acquiescence bias.

The instrument uses a 5-point Likert scale ranging from 1 (Strongly Disagree) to 5 (Strongly Agree). This format permits meaningful variation and is consistent with widely used racial identity and discrimination instruments. Likert scaling is appropriate for measuring internal perceptions and supports psychometric analyses including factor analysis and reliability estimation (Nunnally, 1978).

All items are scored 1–5. Reverse-coded items use the formula: Reverse score = 6 − raw score. Each subscale (4 items) yields a score from 4–20. The Healthcare Stigma Burden Index

(Subscales 1–4) ranges from 16–80; higher scores indicate greater perceived stigma burden. The Stigma Resistance Score (Subscale 5) ranges from 4–20; higher scores reflect stronger resistance and identity affirmation. The SCHRSS total score ranges from 20–100. Interpretation must prioritize subscale profiles over global scores. If one or fewer items are missing within a subscale, scores should be prorated; more than one missing item renders that subscale invalid.

Content validity will be established through structured expert review by specialists in SCD, Black health equity, and social work measurement using a Content Validity Index (Polit & Beck, 2006). Methodologically and ethically, it is essential that I integrate the perspectives of community, Black adults living with SCD. Therefore, I will hold targeted focus groups to guide this work. Construct validity will be assessed via confirmatory factor analysis (CFA) testing the proposed five-factor model (Hu & Bentler, 1999). Criterion validity will be examined through correlations with the Perceived Racism Scale, the PROMIS Pain Interference scale, and the PHQ-9. Stigma Burden Index scores are expected to correlate positively with pain interference and depressive symptoms; Stigma Resistance Scores may show protective associations with quality-of-life outcomes. Internal consistency reliability will be assessed via Cronbach's alpha and inter-item correlations for each subscale, targeting $\alpha \geq .70$ (Nunnally, 1978). Test-retest reliability will be examined across a three-week interval using intraclass correlation coefficients (ICCs), targeting a minimum ICC of .70 (Koo & Li, 2016).

Developing this instrument is an act of empowerment. I have come to this work as a Black social worker who has personally experienced provider dismissal in emergency settings during a sickle cell pain crisis. This lived experience shaped every design decision from the language of individual items to the decision to include resistance as a distinct subscale. Not measuring resistance would replicate the very deficit framing that SCD patients encounter in

healthcare every day. There are real ethical risks here. A stigma scale can be misused to individualize what is structurally produced to resign the problem to the patient's perception rather than in the provider's behavior or the institution's policy. The scoring framework guards against this by discouraging reliance on a single global score and emphasizing structural interpretation. Community accountability is built into the validity process: focus groups with SCD patients are essential because those most affected by this instrument hold the most legitimate authority over whether it captures their experience. Measurement in healthcare settings carries power, and that power has historically been exerted against Black patients. This instrument is designed to change that dynamic, giving language and numerical weight to experiences that have too often been dismissed as subjective or drug motivated. Building this scale deepened my conviction that rigorous social work research requires both methodological precision and honest reckoning with who I am as a researcher, what I bring into the work, and whose reality to which I am accountable.

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APPENDIX

Sickle Cell Healthcare Racial Stigma Scale (SCRHSS)

Instructions: The following statements describe experiences that people with sickle cell disease may have in healthcare settings. Please indicate how much you agree or disagree with each statement based on your personal experiences. There are no right or wrong answers. Your honest responses are important.

Response Scale: 1 = Strongly Disagree | 2 = Disagree | 3 = Neutral | 4 = Agree | 5 = Strongly Agree

#	Item	Subscale	(R)	Response
Subscale 1: Perceived Provider Stigma (PPS)				
1	Healthcare providers have questioned whether my pain is as severe as I say it is.	PPS		1 2 3 4 5
2	I believe providers make assumptions about me as a patient because I am Black.	PPS		1 2 3 4 5
3	Overall, I feel that medical staff treat me with the same respect they give other patients.	PPS	R	1 2 3 4 5
4	I have felt judged or stereotyped by healthcare providers during a sickle cell crisis.	PPS		1 2 3 4 5
Subscale 2: Institutional Devaluation and Exclusion (IDE)				
5	I have had to wait significantly longer than other patients to receive pain treatment in the ER.	IDE		1 2 3 4 5
6	I feel that healthcare systems are not designed with patients like me in mind.	IDE		1 2 3 4 5
7	The healthcare institutions I use generally treat people with sickle cell disease fairly.	IDE	R	1 2 3 4 5
8	I have been denied or delayed care that I believed I needed because of assumptions about drug-seeking.	IDE		1 2 3 4 5
Subscale 3: Psychological Burden of Healthcare Stigma (PBHS)				
9	I feel anxious or stressed before going to the hospital or emergency room because of how I might be treated.	PBHS		1 2 3 4 5
10	It is emotionally exhausting to constantly have to prove that my pain is real to medical staff.	PBHS		1 2 3 4 5
11	I generally feel at ease when seeking medical care for my sickle cell disease.	PBHS	R	1 2 3 4 5
12	Experiences of being doubted or dismissed in healthcare settings have affected my mental health.	PBHS		1 2 3 4 5
Subscale 4: Protective Vigilance and Self-Advocacy (PVSA)				

#	Item	Subscale	(R)	Response
13	I bring written documentation of my medical history to healthcare visits to prevent being dismissed.	PVSA		1 2 3 4 5
14	I carefully manage how I present my pain in healthcare settings to avoid being labeled as drug-seeking.	PVSA		1 2 3 4 5
15	I feel comfortable asking healthcare providers to adjust my treatment without worrying about their reaction.	PVSA	R	1 2 3 4 5
16	I rehearse what I will say to providers before appointments to make sure I am taken seriously.	PVSA		1 2 3 4 5
Subscale 5: Stigma Resistance and Identity Affirmation (SRIA)				
17	I refuse to let negative healthcare experiences make me feel ashamed of living with sickle cell disease.	SRIA		1 2 3 4 5
18	I draw strength from the sickle cell community and Black culture when navigating difficult healthcare experiences.	SRIA		1 2 3 4 5
19	Negative experiences with providers have made me doubt whether I deserve good care.	SRIA	R	1 2 3 4 5
20	I maintain a strong sense of who I am regardless of how healthcare providers treat me.	SRIA		1 2 3 4 5

Scoring Notes

Reverse-scored items (R): Items 3, 7, 11, 15, 19. Formula: Reverse score = 6 − raw score.

Healthcare Stigma Burden Index (HSBI): Sum of Subscales 1–4 (range: 16–80). Higher scores = greater perceived stigma burden.

Stigma Resistance Score (SRS): Subscale 5 only (range: 4–20). Higher scores = stronger resistance and identity affirmation.

SCHRSS Total Score: All subscales combined (range: 20–100). Interpret subscale profiles — do not rely on total score alone.

Missing data: Prorate subscale score if ≤ 1 item missing. Subscale is invalid if > 1 item is missing.