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Perceived Scarcity as a Health Determinant in Adult Sickle Cell Disease

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Abstract

Sickle cell disease (SCD) and other hemoglobinopathies present a compelling case for examining how perceived scarcity operates as an understudied yet essential social determinant of health. While traditional frameworks have focused on objective measures of poverty and resource deprivation, the construct of perceived scarcity encompasses subjective experiences of inadequacy across material, temporal, and psychological domains. This conceptual review proposes that perceived scarcity may function as a mediating mechanism through which structural disadvantage, systemic racism, and chronic illness burden converge to shape clinical outcomes in African American and global populations affected by hemoglobinopathies. Drawing upon behavioral economics, neuroscience, health psychology, and social epidemiology, we examine how perceived scarcity may contribute to neurobiological and cognitive changes, including tunneling, executive function impairment, and maladaptive coping patterns. We propose that perceived scarcity may operate as a distinct pathway from objective poverty, creating psychological states that fundamentally alter decision-making capacity, stress physiology, and health behaviors among individuals managing complex chronic illnesses. This framework suggests capitalist economic structures and systemic racism may contribute to scarcity experiences that transcend individual circumstances, creating cyclical patterns of disadvantage particularly pronounced among marginalized communities. We identify critical gaps in current research methodologies and propose that the Perceived Scarcity Scale may offer a more nuanced assessment than traditional socioeconomic measures for understanding health disparities in hemoglobinopathies. This analysis offers a theoretical foundation and conceptual model for developing interventions that address the psychological and social roots of health inequities rather than merely treating material symptoms.

Introduction

Hemoglobinopathies, particularly sickle cell disease, present one of the most striking examples of how social determinants of health shape clinical outcomes in genetically determined conditions. Despite sharing identical genetic mutations, individuals with SCD demonstrate remarkable variability in disease severity, complications, quality of life, and mortality that cannot be

explained by biological factors alone.[1] In the United States, SCD disproportionately affects African Americans, with approximately 100,000 individuals living with the condition. Globally an estimated 300,000 children are born annually with hemoglobinopathies, in sub-Saharan Africa, India, and the Mediterranean region.[2] The persistent disparities in outcomes between affluent and disadvantaged populations, between well-resourced and under-resourced healthcare systems, and across racial and ethnic groups underscore the profound influence of social factors on disease trajectories.

Traditional approaches to understanding these disparities have relied heavily on objective measures of socioeconomic status including income, education, and employment, alongside assessments of healthcare access barriers such as insurance coverage and geographic proximity to specialized care. While these frameworks have illuminated important structural determinants of health inequity, they inadequately capture the lived experience of individuals navigating chronic illness under conditions of disadvantage.[3] Recent theoretical developments in behavioral economics and psychology suggest that the subjective experience of scarcity, distinct from objective resource deprivation, exerts independent and profound effects on cognition, behavior, and physiology.[4] This perceived scarcity operates across multiple dimensions including material resources, time, cognitive bandwidth, social capital, and psychological wellbeing, creating a comprehensive state of experienced inadequacy. Aberrations within these dimensions may fundamentally alter how individuals make decisions, manage stress, and engage with healthcare systems.[5]

The construct of perceived scarcity, as distinguished from objective poverty or material deprivation, encompasses the subjective sense that one lacks sufficient resources to meet demands across multiple life domains.[5] This psychological state emerges not simply from absolute resource levels but from the relationship between available resources and perceived needs. This psychological state is influenced by social comparisons, temporal pressures, competing demands, and structural constraints.[5] Importantly, perceived scarcity can exist even in the presence of objectively adequate resources when demands exceed capacity to deploy those resources effectively. Conversely, individuals with limited objective resources may not experience perceived scarcity when demands are manageable and social support is robust.[6] This distinction between objective and perceived scarcity has critical implications for understanding health disparities in hemoglobinopathies, where the burden of chronic disease management interacts with social disadvantage to create unique forms of resource inadequacy.[3]

For individuals with SCD, perceived scarcity may arise from the intersection of multiple sources, including the economic burden, employment discrimination, and reduced work capacity. The temporal demands of complex disease self-management compete with other responsibilities, the cognitive load of pain management, and healthcare navigation.[7] These demands must be met when cognitive bandwidth is compromised by pain and stress, the social isolation resulting from disease stigma, and unpredictable symptom patterns.[8] At the same time, inidividuals must contend with the psychological burden of managing an unpredictable, painful, and life-threatening condition within healthcare systems that often provide inadequate and stigmatizing care.[7,8] These experiences of scarcity occur within broader contexts of structural racism, economic inequality, and healthcare system failures that disproportionately affect African Americans and other marginalized communities. Consequently, creating conditions wherein perceived scarcity becomes both a cause and consequence of health disparities.[9,10] (Figure 1)

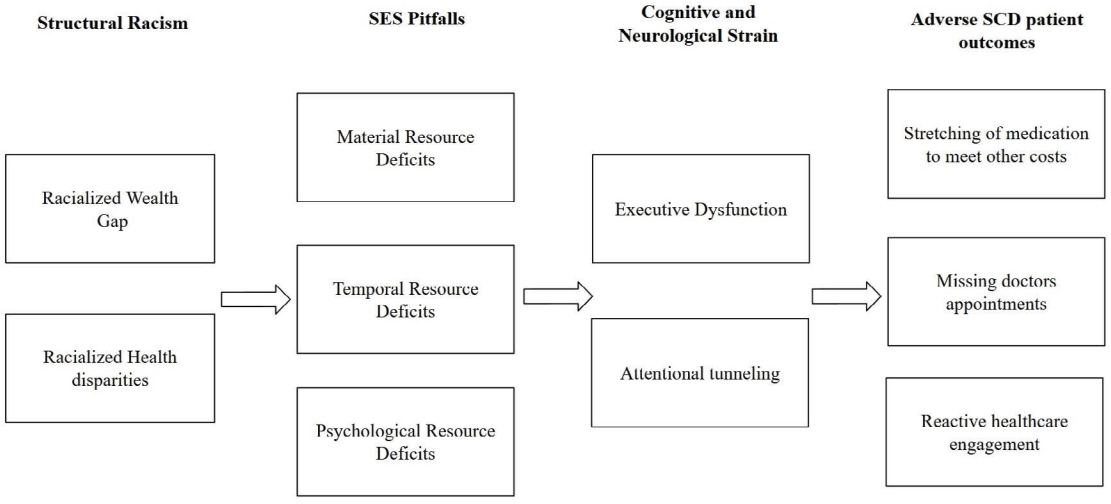

Figure 1: Perceived Scarcity Exacerbation of SCD Health Outcomes—Proposed conceptual model highlighting the causal pathway of perceived scarcity exacerbating health outcomes in SCD patients.

This paper aims to examine neurobiological mechanisms through which perceived scarcity affects brain function and stress physiology. It explores the psychological processes that emerge under conditions of scarcity, including cognitive tunneling and executive dysfunction. It also analyzes how perceived scarcity may interact with structural factors, including systemic racism and capitalism, to perpetuate health inequities. Finally, it considers the role of maladaptive coping strategies, such as John Henryism, that arise in response to chronic experiences of scarcity. We theorize that perceived scarcity represents a critical yet understudied mechanism linking social disadvantage to clinical outcomes in hemoglobinopathies. We further argue that addressing health disparities requires interventions that target the subjective experience of scarcity, rather than focusing solely on the provision of objective resources.

Methodology

This manuscript represents conceptual narrative review synthesizing evidence from neuroscience, behavioral economics, health psychology, and social epidemiology to develop a framework for understanding how perceived scarcity may operate as a social determinant of health in hemoglobinopathies. A structured literature search was conducted in November 2025 using PubMed, Google Scholar, and APA PsycNet. No date restrictions were applied to allow inclusion of both foundational and contemporary literature. Search terms included combinations of perceived scarcity, scarcity, poverty, stress, cognition, decision-making, sickle cell disease, and hemoglobinopathies.

Peer-reviewed empirical studies, theoretical articles, reviews, and meta-analyses published in English were eligible for inclusion. Articles were selected based on relevance to the conceptual domains of interest, including psychological and behavioral effects of scarcity, neurobiological and physiological stress mechanisms, structural and social determinants of health, and clinical or psychosocial factors relevant to hemoglobinopathies. Additional sources were identified through reference list review of key publications. Literature was excluded if it lacked peer-review or was not currently published in the English language.

Because the purpose of this work was theory development and conceptual integration, studies were not screened using formal systematic review procedures and no quantitative synthesis was performed. As a narrative review, the literature selection was guided by conceptual relevance and does not represent a comprehensive or exhaustive synthesis of all available studies. As a narrative review, the manuscript may not represent a comprehensive synthesis of all available studies, and selection bias is possible.

Theoretical Framework

The theoretical framework of scarcity developed by Mullainathan and Shafir revolutionized understanding of how resource limitations affect human cognition and behavior. Their seminal work demonstrated that scarcity captures attention and cognitive bandwidth involuntarily. Thus, perpetuating a psychological state characterized by tunneling, wherein focus narrows intensely toward addressing the scarce resource while simultaneously impairing executive function and future-oriented planning.[11] This scarcity mindset emerges regardless of the specific domain of scarcity, whether financial, temporal, or social, suggesting common psychological mechanisms underlying responses to resource inadequacy across contexts. Critically, their research revealed that the cognitive consequences of scarcity may be substantial and occur independently of individual capacity. Experimental manipulations of scarcity were shown to impair fluid intelligence, executive control, and decision-making quality, with effects comparable to losing an entire night of sleep or experiencing significant reductions in IQ.[11]

While Mullainathan and Shafir's framework focused primarily on the cognitive consequences of objective scarcity, subsequent research has elaborated on the importance of perceived or subjective scarcity as distinct from objective resource limitations. The development of the Perceived Scarcity Scale represents a measurement of subjective scarcity experiences across multiple domains, including financial, temporal, and social dimensions.[12] This scale assesses not merely whether individuals possess adequate resources in objective terms but rather whether they experience their resources as sufficient relative to demands. Therefore, capturing the psychological reality of scarcity that may occur even when objective resources appear adequate or conversely may be absent even when resources are objectively limited.[5] The distinction between objective and perceived scarcity parallels broader recognition in health research that subjective social status, reflecting individuals' perceptions of their standing in social hierarchies, predicts health outcomes independently of and sometimes more strongly than objective socioeconomic indicators.[12]

The construct of perceived scarcity extends traditional economic conceptualizations of scarcity as simple insufficiency of material goods to encompass psychological experiences of inadequacy across multiple life domains. Material or financial scarcity reflects the subjective evidence of economic insufficiency, including worry about meeting basic needs, inability to afford unexpected expenses, and chronic financial stress that persists even when income exceeds poverty thresholds.[5] Temporal scarcity encompasses the subjective sense of time poverty, experiencing insufficient time to meet role demands and

responsibilities, creating chronic feelings of being rushed and overwhelmed.[5] Psychological resource scarcity captures perceived inadequacy of interpersonal (social connections, support, and belonging) and intrapersonal resources, feelings of low self-worth, limited personal agency, and inability to meet personal standards or goals. The Perceived Scarcity Scale encapsulate these domains within 24-items that have been empirically validated as distinct concepts The Perceived Scarcity Scale is designed to assess subjective experiences of resource inadequacy across three domains: material (financial and basic resource strain), temporal (perceived time pressure), and psychological resources (including perceived limitations in social support, self-efficacy, and personal capacity). [5] The scale captures the extent to which individuals experience their available resources as insufficient relative to their demands across several populations.[5]

These dimensions of perceived scarcity are conceptually distinct yet empirically interrelated, often occurring simultaneously and interacting synergistically to compound effects on wellbeing and health. For individuals with hemoglobinopathies, particularly SCD, the complex demands of chronic disease management create conditions conducive to perceived scarcity across all dimensions. The unpredictability of pain crises creates both temporal scarcity, as individuals cannot reliably plan time allocation, and cognitive obstruction, as pain and its management consume mental bandwidth.[13] The economic burden of medical care combined with employment discrimination and reduced work capacity creates material scarcity that extends beyond what might be predicted from income alone when accounting for disease-related expenses.[7] The social stigma associated with SCD, particularly stereotypes regarding drug-seeking behavior, creates psychological scarcity through isolation and damaged healthcare relationships.[8,9] The psychological burden of managing an unpredictable, painful, and potentially life-threatening condition creates psychological scarcity manifested in anxiety, depression, and diminished sense of agency.

Measurement of perceived scarcity requires attention to both domain-specific experiences and overall scarcity burden. The Perceived Scarcity Scale assesses subjective experiences across financial, temporal, and social domains through items capturing worry, stress, and feelings of inadequacy related to each domain.[12] This approach complements traditional socioeconomic status measures by capturing subjective experiences that may diverge from objective circumstances. For example, two individuals with identical incomes may experience vastly distinct levels of financial scarcity depending on expenses, debts, family obligations, and psychological factors influencing their sense of financial security. Similarly, two individuals spending identical hours on disease management may experience various levels of temporal scarcity depending on competing demands, social support reducing time burden, and psychological resources affecting subjective time pressure. Understanding perceived scarcity, therefore, requires assessment of subjective experiences rather than relying solely on objective indicators. This remains a distinction with important implications for identifying individuals at highest risk for adverse outcomes and for designing interventions addressing root causes of health disparities.

Neurobiological Mechanisms

The neurobiological consequences of perceived scarcity provide mechanistic insights into how subjective experiences of resource inadequacy translate into altered cognition, behavior, and health outcomes. Neuroimaging research has identified specific brain regions involved in processing scarcity, with the orbitofrontal cortex demonstrating sensitivity to perceived resource limitations. The orbitofrontal cortex plays crucial roles in decision-making, reward evaluation, and adaptive response to changing environmental circumstances.[14] Under conditions of perceived scarcity, this region shows altered activation patterns associated with increased focus on immediate rewards and resources. [14] Additionally, research has also demonstrated reduced sensitivity to future consequences and long-term planning considerations.[14] These neurobiological changes correspond to the behavioral pattern of tunneling described in scarcity theory, wherein attention narrows toward immediate scarcity-related concerns at the expense of broader perspective and future orientation.[15]

The prefrontal cortex, encompassing regions critical for executive functions including working memory, cognitive flexibility, inhibitory control, and planning, demonstrates impaired function under conditions of perceived scarcity.[14] Neuroimaging studies reveal that scarcity-related stress is consistent with reducing prefrontal cortex activation during tasks requiring executive control, with corresponding decrements in behavioral performance on measures of working memory capacity, attentional control, and impulse regulation.[14] These neural changes suggest that the cognitive bandwidth tax associated with scarcity. The experience of resource may inadequately consume cognitive resources that would otherwise be available for complex decision-making, self-regulation, and goal-directed behavior.[15] For individuals managing chronic conditions like SCD, which inherently demand substantial executive function for medication adherence and health care utilization, scarcity-induced impairments in prefrontal function are hypothesized to create significant barriers to optimal self-management.

The hypothalamic-pituitary-adrenal axis represents

a critical neurobiological pathway linking perceived scarcity to physiological stress responses and to health outcomes. In this framework, perceived scarcity is hypothesized to influence multiple components of HPA-axis functioning, including alterations in diurnal cortisol rhythms, heightened cortisol responses to acute stressors, and delayed physiological recovery following stress. These patterns are conceptually consistent with broader chronic stress physiology. It remains unclear whether scarcity-related alterations are distinguishable from general stress-related HPA dysregulation. Future research will require assessment of multiple HPA-axis indices, including diurnal patterns and stress reactivity, to determine whether perceived scarcity is associated with distinct physiological profiles. Chronic experiences of scarcity are hypothesized to activate this stress axis, leading to sustained elevation of cortisol and other stress hormones. While acute cortisol elevation serves adaptive functions in mobilizing resources to address threats, chronic HPA axis activation produces deleterious effects across multiple physiological systems.[14] Elevated cortisol promotes inflammation, impairs immune function, increases blood pressure, promotes insulin resistance and metabolic dysfunction, alters pain perception and pain processing, and affects brain structure and function, including hippocampal volume reduction associated with memory impairment.[16,17] These physiological consequences of chronic stress have particular relevance for SCD, in which inflammation and vaso-occlusion underlie the disease pathophysiology. Pain is a central feature of the condition and requires complex management.[18]

The relationship between perceived scarcity and HPA axis dysregulation extends beyond simple stress exposure to encompass alterations in stress reactivity and recovery. Existing research on chronic stress and resource-related strain suggests patterns including flattened diurnal cortisol rhythms, exaggerated cortisol responses to acute stressors, and impaired cortisol recovery following stress exposure, although the extent to which these patterns are specific to perceived scarcity remains unclear.[19,20] These patterns of HPA axis dysregulation have been linked to accelerated biological aging, increased disease risk, and worse outcomes across diverse health conditions.[21,22] For individuals with SCD, chronic pain, unpredictable disease complications, healthcare discrimination, and significant socioeconomic disadvantage converge to create conditions conducive to severe HPA-axis dysregulation. The resulting physiological burden may directly exacerbate disease complications by promoting inflammation and vaso-occlusion. At the same time, it may impair the capacity for effective self-management through its effects on cognition, mood, and behavior.

The neurobiological impacts of perceived scarcity also encompass alterations in reward processing and dopaminergic signaling, with implications for motivation, pleasure, and behavioral responses to incentives. Research indicates that chronic scarcity experiences alter striatal dopamine function, reducing reward sensitivity and promoting preference for immediate over delayed rewards.[15] These neurobiological changes correspond to behavioral patterns often observed among individuals experiencing chronic disadvantage. These patterns include present-focused decision-making, reduced engagement in preventive health behaviors that offer delayed benefits, and increased risk of substance use and other behaviors that provide immediate reward.[5,23] Understanding these patterns as neurobiological consequences of perceived scarcity rather than character flaws or poor choices represents an important reframing with implications for clinical practice and intervention design. For individuals with SCD navigating complex treatment regimens requiring consistent adherence despite lack of immediate benefit, scarcity-induced alterations in reward processing may significantly impair capacity to sustain health-promoting behaviors.

Tunneling, Executive Dysfunction, and Decision-Making Under Scarcity

The cognitive consequences of perceived scarcity extend beyond specific neurobiological alterations to encompass broader changes in information processing, attention allocation, and decision-making patterns. Tunneling represents a central feature of the scarcity mindset, characterized by intense focus on immediate scarcity-related concerns accompanied by reduced attention to peripheral information and future consequences.[12] While tunneling can enhance performance on tasks related to managing scarcity, it simultaneously impairs broader perspective, creative problem-solving, and attention to matters not immediately related to the scarce resource.[12] This narrowed attentional focus has significant implications for chronic disease management. For example, optimal outcomes depend on balancing immediate symptom management with preventive behaviors, long-term planning, and attention to multiple health domains simultaneously.

For individuals with hemoglobinopathies, the experience of tunneling induced by perceived scarcity manifests in predictable patterns of healthcare engagement and self-management. Financial scarcity creates tunneling toward immediate economic survival, potentially leading to deferral of preventive medical care, stretching of medications to reduce pharmacy costs, and delayed care-seeking for acute symptoms to avoid emergency department expenses.[12,14] Temporal scarcity produces tunneling toward immediate temporal demands, resulting in missed medical appointments when work obligations

conflict, reduced time for meal preparation and health-promoting behaviors, and reactive rather than proactive healthcare engagement.[21] Cognitive obstruction, often resulting from pain or stress, creates tunneling toward immediate symptom relief at the expense of sustained attention to medication adherence, symptom tracking, and healthcare communication.[9,12] Understanding these patterns through the lens of scarcity-induced tunneling reframes behaviors often labeled as non-adherence or irresponsibility as predictable psychological responses to resource inadequacy.

Executive function impairments associated with perceived scarcity encompass deficits across multiple cognitive domains, including working memory, cognitive flexibility, inhibitory control, and planning ability.[12] Working memory deficits reduce capacity to hold and manipulate information mentally, affecting the ability to track medication schedules, remember healthcare provider instructions, and integrate information across medical appointments. Impaired cognitive flexibility reduces the capacity to adapt strategies when circumstances change, leading to rigid behavioral patterns even when circumstances benefit from adjustment. Diminished inhibitory control reduces the capacity to resist immediate temptations in the service of long-term goals, affecting adherence to dietary restrictions, substance use avoidance, and other health behaviors requiring self-regulation. Planning impairments reduce capacity for future-oriented goal setting and strategic health behavior change. Collectively, these executive function deficits create significant barriers to effective chronic disease self-management.

The decision-making patterns observed under conditions of perceived scarcity reflect rational adaptation to cognitive constraints and environmental demands rather than representing cognitive incapacity or poor judgment.[23] When cognitive bandwidth is taxed by scarcity concerns, individuals appropriately prioritize decisions with immediate and certain consequences while deferring or simplifying decisions with delayed or uncertain outcomes.[23] This adaptation preserves limited cognitive resources for the most pressing concerns but has the unintended consequence of potentially compromising long-term health through underinvestment in preventive care and health promotion. Research demonstrates that perceived scarcity increases risk-taking in some domains while increasing risk-aversion in others, with patterns dependent on whether risky options offer potential escape from scarcity conditions.[21] For individuals with SCD facing multiple concurrent scarcities, decision-making about healthcare utilization, treatment adherence, and health behaviors involve complex trade-offs between competing needs and values. Optimal choices from a long-term health perspective often require cognitive resources that scarcity has rendered unavailable.

The psychological consequences of chronic perceived scarcity also encompass emotional and motivational effects including increased anxiety and depression, reduced sense of agency and self-efficacy, and diminished hope and future orientation.[24] These psychological sequelae both result from and contribute to perceived scarcity. This often leads to creating potential for cyclical patterns wherein scarcity produces psychological distress that further impairs coping capacity and exacerbates subjective experiences of inadequacy. For individuals with hemoglobinopathies, the psychological burden of chronic illness compounds scarcity-related distress. The unpredictability of symptoms, pain-related suffering, frustrations with the healthcare system, and social stigma all contribute to adverse psychological outcomes.[8,9] Evidence from chronic disease populations shows that prolonged stress exposure is associated with altered cortisol regulation, increased inflammatory activity, and greater cumulative physiological burden.[3,17,18] These processes are especially relevant for conditions characterized by chronic pain and recurrent medical complications. In sickle cell disease, ongoing pain, frequent healthcare utilization, and persistent psychosocial stressors may contribute to sustained physiological stress that interacts with disease-related biological pathways.[3,17,18] The intersection of disease-related psychological burden and scarcity-related distress creates conditions conducive to severe mental health problems, including major depression, anxiety disorders, and trauma-related conditions. Yet, mental health services remain inadequately accessed by many individuals with SCD due to stigma, insurance barriers, and provider shortages, representing another dimension of healthcare scarcity.[3,8,9]

Although scarcity is often associated with cognitive burden and impaired decision-making, its effects are context dependent.[11] Under certain conditions, scarcity-induced tunneling may enhance attention to high-priority tasks and improve short-term performance on goals that are directly linked to the scarce resource.[4,11] These adaptive effects may be beneficial when immediate demands are clearly defined, but they may come at the cost of reduced attention to longer-term planning and competing priorities.[11] Factors that reduce cognitive burden may help buffer the effects of scarcity-related tunneling and executive strain. Supportive resources such as strong social networks, coordinated care, and patient navigation services can lessen the mental demands associated with managing appointments, medications, transportation, and administrative requirements. By shifting some planning and problem-solving responsibilities outside the individual, these supports may help preserve cognitive bandwidth, facilitate more consistent healthcare engagement, and

reduce the functional impact of perceived scarcity among individuals with hemoglobinopathies.

John Henryism and Maladaptive Coping

The construct of John Henryism represents a culturally specific coping pattern with relevance for understanding responses to perceived scarcity among African American populations affected by hemoglobinopathies. John Henryism is defined as a behavioral predisposition toward sustained, high-effort coping with psychosocial and environmental stressors despite inadequate resources for success. It captures a pattern of determined striving against systemic obstacles that may initially appear adaptive but exacts severe physiological costs.[25] The construct was named after the legendary folkloric steel driver who, according to African American folklore, died from exhaustion after outperforming a steam-powered drill. John Henryism reflects cultural values of perseverance, self-reliance, and determination in the face of adversity while simultaneously highlighting the health consequences of sustained high-effort coping when structural barriers remain unaddressed.[25]

Research examining John Henryism among African Americans has consistently demonstrated associations with adverse cardiovascular outcomes, particularly when combined with low socioeconomic status.[21,26] The pattern suggests that individuals exhibiting high John Henryism who possess adequate resources to achieve goals experience no adverse health effects. Conversely, those with high John Henryism and low resources demonstrate elevated risk for hypertension, cardiovascular disease, and stroke.[21,26] This interaction between coping style and resource availability illuminates mechanisms through which perceived scarcity translates into health disparities. When individuals experience perceived scarcity across multiple domains yet maintain high-effort coping strategies in attempts to overcome barriers, the resulting chronic physiological activation produces cumulative biological burden despite conscientious efforts toward goal achievement.[21,26]

For individuals with SCD, John Henryism may manifest in patterns of sustained effort to maintain employment despite chronic pain and fatigue. Examples of this include perseverance in managing complex healthcare demands without adequate support or resources, determination to maintain family and social responsibilities despite disease burden, and continued efforts to achieve educational and career goals despite systemic barriers and discrimination. While these coping efforts reflect admirable resilience and determination, the sustained high-effort exertion under conditions of inadequate resources creates the conditions demonstrated to produce adverse cardiovascular outcomes through chronic stress activation. The unpredictability of SCD complications further compounds this burden, as even maximal effort cannot guarantee symptom control or prevent acute crises. The complications and high effort coping often leads to chronic uncertainty and uncontrollability that amplify stress responses.[27]

The relationship between perceived scarcity and John Henryism reveals important insights into how structural disadvantages translate into individual health outcomes through psychological and behavioral pathways. Perceived scarcity creates conditions motivating high-effort coping as individuals attempt to overcome resource limitations and achieve goals despite constraints.[23] This high-effort response may succeed in the short term, enabling individuals to maintain employment, meet responsibilities, and achieve specific objectives despite scarcity conditions. However, when scarcity is chronic and structural barriers remain in place, sustained high-effort coping without corresponding resource adequacy or environmental support produces physiological burden through chronic stress activation, compromising health outcomes.[22] This mechanism illustrates how individual-level coping strategies, even those reflecting cultural strengths and values, cannot fully overcome structural disadvantage without complementary environmental changes addressing root causes of scarcity.

The implications of John Henryism for understanding health disparities in SCD extend beyond cardiovascular outcomes to encompass broader impacts on disease management and quality of life. The determined perseverance characteristic of John Henryism may promote treatment adherence and engagement with healthcare, potentially conferring some benefits for disease management.[28] However, the psychological and physiological costs of sustained high-effort coping under conditions of chronic scarcity and structural barrier may overwhelm any benefits from enhanced healthcare engagement.[9,13,23] Furthermore, the focus on individual effort and perseverance inherent in John Henryism may inadvertently discourage help-seeking, reduce willingness to acknowledge limitations, and promote self-blame when outcomes remain poor despite maximal effort.[21] These unintended consequences of high-effort coping highlight the importance of interventions addressing structural sources of scarcity rather than simply encouraging individuals to work harder within constraining circumstances.

Systemic Racism in Hemoglobinopathies

The experiences of perceived scarcity among individuals with hemoglobinopathies cannot be understood apart from broader structural contexts of systemic racism and capitalist economic organization that create and perpetuate conditions of disadvantage.[29,30] Systemic racism encompasses the policies, practices, and cultural norms embedded within social institutions that

produce and maintain racial inequality.[29] These structural factors operate across multiple domains. Employment discrimination limits job opportunities and wage growth.[29] Residential segregation concentrates poverty and restricts access to quality education and healthcare.[29] Bias within the healthcare system produces disparities in diagnosis, treatment, and pain management. Inequities in the criminal justice system disproportionately affect communities of color.[29] Political disenfranchisement limits the capacity to influence policies that affect health and wellbeing.[29] For African Americans with SCD, systemic racism creates layered disadvantages wherein disease-related vulnerabilities compound existing structural barriers, producing particularly severe experiences of scarcity.

The economic structure of capitalism creates conditions conducive to scarcity experiences even among employed individuals through mechanisms including wage stagnation despite productivity gains. These conditions lead to declining real wages for workers and precarious employment arrangements, including part-time and contract work without benefits or job security. Inadequate social safety nets provide insufficient support during periods of unemployment or illness. Healthcare systems that prioritize profit over access and quality create financial barriers to necessary care. Housing markets produce unaffordable costs that consume a large portion of income.[29] These structural features create economic scarcity that extends beyond individual circumstances to reflect systemic features of economic organization. For individuals with SCD, whose employment is often disrupted by unpredictable disease complications and who face substantial healthcare costs even with insurance, causing financial vulnerability.

The intersection of systemic racism and capitalism produces compounded disadvantage for African Americans with hemoglobinopathies through multiple pathways. Employment discrimination limits job opportunities and advancement, reducing earning capacity and economic security.[7] Residential segregation concentrates individuals in neighborhoods with limited economic opportunity, poor housing quality, environmental hazards, and inadequate healthcare infrastructure.[31] Healthcare system bias produces inadequate pain management, delayed diagnosis of complications, and skepticism regarding symptom reports, creating barriers to necessary care while simultaneously eroding trust in healthcare relationships.[9] Educational inequities limit opportunities for skill development and credential acquisition necessary for economic mobility.[32] Criminal justice involvement, occurring disproportionately in communities of color, creates lasting barriers to employment, housing, and social participation.[33] These multiple dimensions of structural disadvantage operate synergistically to create chronic experiences of scarcity that transcend individual circumstances or choices.

The perpetuation of scarcity through structural mechanisms creates cyclical patterns wherein scarcity produces consequences that further entrench disadvantage. Economic scarcity limits access to health-promoting resources, including nutritious food, safe housing, and healthcare, producing health problems that reduce work capacity and earning potential.[21] Temporal scarcity resulting from juggling multiple low-wage jobs or managing healthcare appointments without reliable transportation reduces capacity for skill development, education, or job searching that might improve economic circumstances.[21] Intrapersonal psychological resource scarcity resulting from chronic stress and resource juggling impairs decision-making and planning capacity necessary for economic advancement or health behavior change.[14,23,21] Interpersonal psychological resource scarcity resulting from stigma, discrimination, and geographic isolation reduces access to social networks that might provide job opportunities, practical support, or emotional resources.[23,21] These cyclical patterns create poverty traps wherein individuals work extraordinarily hard yet remain unable to escape scarcity conditions due to structural barriers and accumulated disadvantages.

Although these patterns vary across settings, the structural conditions shaping perceived scarcity also differ substantially across national contexts. Differences in healthcare financing, social welfare protections, disability support, employment policies, and access to paid leave influence the extent to which individuals with hemoglobinopathies experience financial, temporal, and administrative burden. In settings with limited insurance coverage or weak social safety nets, patients may face higher out-of-pocket costs, fragmented care, and greater responsibility for coordinating services. Even in higher-resource systems, bureaucratic complexity, eligibility restrictions, and gaps in coverage can create administrative burden that contributes to time scarcity and cognitive strain. These variations highlight how system design and policy implementation may either mitigate or amplify perceived scarcity, underscoring the need for structural approaches that reduce financial risk, simplify care navigation, and support long-term disease management.

Understanding health disparities in hemoglobinopathies requires recognition that perceived scarcity reflects not merely individual circumstances, but rather structural conditions systematically distributed along lines of race, class, and other social positions. Interventions focused solely on individual-level changes in behavior, knowledge, or coping cannot address health disparities when structural factors continue producing scarcity experiences. Achieving health equity requires structural interventions addressing

the root causes of scarcity. These include policies promoting living wages and employment security. They also include investments in affordable housing and neighborhood resources. Universal healthcare coverage eliminating financial barriers to necessary care is another key intervention. Anti-discrimination enforcement protecting employment and housing rights is critical. Finally, criminal justice reform reducing collateral consequences of system involvement is essential. These structural changes would reduce perceived scarcity across populations while simultaneously addressing fundamental sources of health inequity.

Future Directions

Despite growing recognition of perceived scarcity as an important construct for understanding health disparities, significant gaps remain in research examining scarcity experiences across diverse populations and contexts. Current research has focused on general population samples with limited attention to specific populations experiencing chronic illness, particularly hemoglobinopathies. The unique intersection of disease burden, healthcare system navigation, and socioeconomic disadvantage in SCD populations creates conditions producing distinctive patterns of perceived scarcity warranting specific investigation. Research is needed examining how disease-specific factors including pain chronicity, symptom unpredictability, treatment complexity, and healthcare discrimination interact with broader socioeconomic circumstances to shape scarcity experiences in hemoglobinopathies.

Methodological limitations in existing scarcity research include an overreliance on cross-sectional designs, which limits causal inference. There is inadequate attention to diverse racial and ethnic populations, particularly those most affected by health disparities. Research has also provided limited examination of how perceived scarcity changes over time and across life course transitions. There is insufficient investigation of protective factors that might buffer the effects of scarcity. Additionally, there is a lack of intervention research testing whether reducing perceived scarcity improves health outcomes. Addressing these limitations requires longitudinal research designs that follow individuals over time to examine how scarcity experiences and health outcomes co-evolve. It also requires diverse sampling strategies to ensure adequate representation of populations most affected by health disparities. Mixed methods approach combining quantitative measurement of scarcity with qualitative exploration of lived experiences are needed. Intervention studies should test whether addressing various dimensions of scarcity improves psychological, behavioral, and clinical outcomes. Finally, mechanistic studies are needed to examine neurobiological, psychological, and social pathways, linking perceived scarcity to health.

The relationship between demographic variables and perceived scarcity remains inadequately understood despite clear importance for health disparities research. While strong correlations between objective socioeconomic indicators and health outcomes are well-established, the relationships among objective circumstances, perceived scarcity, and health require further elucidation. Research should examine whether perceived scarcity fully mediates the relationship between objective socioeconomic status and health outcomes. It should also investigate whether perceived scarcity predicts health outcomes independently of objective measures. Studies should explore how race, ethnicity, gender, and other social positions influence the relationship between objective circumstances and perceived scarcity. Research should consider whether cultural factors or historical experiences shape how individuals interpret and respond to resource limitations. In addition, studies should examine how chronic illness modifies the relationship between socioeconomic circumstances and experiences of scarcity. These questions have important implications for intervention design and for understanding mechanisms underlying health disparities.

Research examining hemoglobinopathies specifically should investigate how disease-related factors shape perceived scarcity. This includes examining whether the chronicity and severity of pain predict particular dimensions of cognitive and psychological scarcity, how the unpredictability of disease complications affects temporal and planning-related aspects of scarcity, and whether healthcare discrimination and stigma particularly influence social and psychological dimensions of scarcity. Studies should also consider how the timing of disease onset across the life course shapes scarcity trajectories and adaptation, and whether complications such as stroke and chronic organ damage impact cognitive aspects of scarcity through neurological mechanisms beyond purely psychological pathways. Further investigation into the specific neurological pathways induced by perceived scarcity must be highlighted, in order to differentiate these cognitive effects from other disease-related impairments. Additionally, research should examine whether interventions successfully employed in other chronic illness populations transfer effectively to hemoglobinopathies or whether disease-specific features require tailored approaches.

Conclusion

Perceived scarcity may represent an important and understudied social determinant of health with particular importance for understanding disparities in hemoglobinopathies. By examining how subjective experiences of resource inadequacy across material, temporal, and psychological domains may influence health outcomes, the scarcity framework illuminates

mechanisms linking structural disadvantage to individual health trajectories. For individuals with SCD and other hemoglobinopathies, particularly African Americans navigating intersecting disadvantages, perceived scarcity operates as a central organizing feature of lived experience with profound implications for disease management, healthcare engagement, and clinical outcomes.

The proposed neurobiological, cognitive, and psychological consequences of perceived scarcity offer a conceptual understanding of how subjective resource inadequacy translates into impaired decision-making, compromised self-management, chronic physiological stress, and disparate health outcomes. Rather than attributing poor outcomes to individual deficits in knowledge, motivation, or capability, the scarcity framework suggests that environmental conditions and structural inequities may shape psychological states that fundamentally alter cognition and behavior. This reframing has important implications for clinical practice, suggesting the need for healthcare delivery models that minimize cognitive burden, provide comprehensive support for disease management, and acknowledge the realities of patients' lives rather than if education alone will produce behavior change.

The scarcity framework also highlights limitations of interventions focused solely on individual-level change when structural factors continue producing scarcity conditions. While psychological interventions addressing stress, coping, and decision-making may provide some benefit, achieving health equity requires structural changes addressing root causes of scarcity including economic inequality, employment discrimination, healthcare access barriers, and neighborhood disadvantages. Policies promoting living wages, universal healthcare, affordable housing, and anti-discrimination enforcement represent essential components of efforts to reduce scarcity and advance health equity. The recognition that perceived scarcity reflects structural conditions systematically distributed along lines of race and class underscores the inadequacy of approaches treating health disparities as problems of individual behavior requiring only education or motivation.

Future research examining perceived scarcity in hemoglobinopathies should employ rigorous longitudinal designs, diverse sampling strategies, mixed methods approach, and intervention studies testing whether reducing scarcity improves outcomes. The Perceived Scarcity Scale offers a methodological tool enabling more nuanced assessment of subjective resource inadequacy than traditional socioeconomic measures, potentially identifying individuals at highest risk for adverse outcomes and enabling targeted intervention. The Perceived Scarcity Scale was developed through a multi-study validation process and demonstrates strong internal consistency ($\alpha \approx .89–.91$ overall; subscales $\alpha \approx .84 –.89$) and stability over time (test–retest $r \approx .71 –.84$).[25] Evidence for construct validity is supported by strong associations with material hardship ($r \approx .72$), time pressure ($r \approx .60$), and perceived stress ($r \approx .68$), as well as weaker relationships with education and occupational status.[25] Longitudinal analyses further showed that perceived scarcity accounted for additional variance in stress and health-related outcomes beyond income, education, occupation, and subjective social status ($R^2 \approx .05 –.29$).[25] Although these findings support the scale's reliability and initial validity in general populations, its measurement performance in hemoglobinopathy populations has not yet been established. By positioning perceived scarcity as a hypothesized determinant of health, this framework offers a conceptual foundation for future investigation and for the development of multilevel strategies aimed at reducing health disparities.

The scarcity framework provides a unifying lens for understanding how psychological and social factors shape clinical outcomes in chronic illness, demonstrating that disparities reflect not individual failings but rather predictable consequences of structural disadvantage operating through psychological, neurobiological, and behavioral pathways. By centering perceived scarcity as a critical determinant of health, this framework challenges deficit-based explanations for health disparities while simultaneously providing actionable insights for intervention. Achieving health equity for individuals with hemoglobinopathies requires addressing the multiple dimensions of scarcity that shape disease experiences, outcomes, and quality of life, recognizing that optimal health cannot be achieved through medical management alone when scarcity undermines the psychological, cognitive, and material resources necessary for effective self-care and wellbeing.

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Conflict of Interest

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Consent to Participate

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Data Availability

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Use of Artificial Intelligence

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