

Socioeconomic Inequalities And Health System Access In Sickle Cell Disease: A Narrative Review Of Global Evidence

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Abstract: Sickle cell disease (SCD) is an inherited disorder of hemoglobin, characterized by the formation of long chains of hemoglobin when deoxygenated within capillary beds, resulting in sickle-shaped red blood cells, progressive multiorgan damage, and increased mortality. Patients with SCD suffer from numerous complications, including acute and chronic pain and end-organ dysfunction, which require rigorous clinical follow-up and intervention to prevent deterioration of health. In SCD, the burden of managing a chronic illness experiences racial disparities, and other socioeconomic factors like income, education, employment, and health literacy affect health outcomes and quality of life. Thus, the review is conducted to know the depth of the socioeconomic inequalities influencing access to health systems regarding SCD. This is done via the narrative review type. Therefore, as a narrative review, the aim is to investigate the existing studies for the objective of socioeconomic inequalities affecting access to health systems and care for individuals with SCD. Research problems include a lack of access to essential medicines, insufficient pain management, and insufficient specialized care. The issues are compounded by poverty, a poor health care system, and social isolation. As a whole, exploring inequities in SCD treatment is essential from both a clinical and social perspective to deliver full access to health coverage and provide high-quality living conditions for individuals diagnosed with this disease.

Keywords: *Sickle Cell Disease, Health system access, Socio-economic inequalities, Poverty, Income, and Social Determinants.*

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1. INTRODUCTION

Background on Sickle Cell Disease

Sickle Cell Disease (SCD) is a common and life-threatening haematological disorder that affects millions of people worldwide [1]. SCD is a disease that is caused by the formation of an abnormal haemoglobin type, which can bind with other abnormal haemoglobin molecules within the red blood cells (RBCs) to cause rigid distortion of the cell. The formation of polymerized haemoglobin leads to erythrocyte rigidity. Also, the appearance of characteristic sickle-shaped RBCs results in vascular occlusion, and haemolysis is central to the molecular pathogenesis of the disease [2]. As a result, patients with SCD suffer from chronic hemolytic anemia and acute painful vaso-occlusive crises that can lead to a central nervous system vasculopathy, causing impaired intellectual development. This condition affects millions of people worldwide, particularly those of African, Mediterranean, Middle Eastern, and South Asian descent. In sub-Saharan Africa, India, and the Middle East, SCD is prevalent, with

approximately 300,000 infants born annually with the condition [3]. However, in high-income countries (HICs) with less than 5% of the global disease burden, the newborn screening (NBS) and early interventions with comprehensive care are routinely practised. In addition, 95% of children born with SCD survive beyond 18 years of age [4]. Also, SCD causes severe pain, organ damage (kidneys, spleen, and liver), acute chest syndrome, strokes, and heightened infection risk. Children with SCD and their parents suffer from psycho-social, financial, and physical impacts of the disease. SCD places considerable psychosocial and financial strain on affected individuals and families, affecting their education, employment, and overall quality of life. The psychosocial and financial challenges of SCD are compounded by the presence of social determinants of health, such as poverty, low health literacy, and structural inequities in and across health systems. SCD needs complete and equity-based techniques for the purpose of prevention and treatment because of the clinical course related to social and health system factors.

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Rationale for focusing on socioeconomic and health system inequalities

SCD is influenced by several factors, including genes and other clinical conditions; however, it is also greatly influenced by socioeconomic status as well as inequalities in the health care system. Although there are many effective methods for the prevention and treatment of individuals with SCD, rates of positive outcomes for individuals with the condition can vary significantly within and between countries. Significant differences in income, education, and work factors that influence socioeconomic status contribute to delayed diagnosis, inadequate monitoring of the condition, poor adherence to treatment, and increased rates of morbidity and mortality, particularly among individuals with low socioeconomic status.

Additionally, barriers in the health care system that exacerbate inequalities are limited specialized services, fragmented care pathways, and poor quality and/or discriminatory care. Therefore, it is very important to focus on socioeconomic and health system inequalities to understand why there are large disparities in health status among individuals affected by SCD, even though there have been significant advances in the area of medical care. Thus, it is essential to explore the research studies associated with socioeconomic and health system inequalities and identify the gaps in SCD. Exploring socioeconomic as well as health system inequalities helps to provide a clear idea for equity-oriented policies and interventions that improve the healthcare systems for individuals with SCD.

2. Conceptual Framework

2.1 Theoretical Foundations

The narrative review follows a conceptual framework for integrative health. This framework combines many different social determinants of health models and health systems access models to understand why people with SCD experience care and outcome disparities. SCD is a genetic disease; however, many studies indicate that the majority of the course of an SCD case and the overall population experience of SCD are based on the influence of socioeconomic factors and how the healthcare system performs, as opposed to biological factors.

2.2 Structural and Socioeconomic Determinants

To examine individuals with SCD at the structural level, the framework also links them to larger systems, including socio-economic, political, and

social contexts that affect the way they experience resources and opportunities. Examples of key determinants include income and poverty, education level, employment conditions, social protection, and social exclusion.

2.3 Health System Access Dimensions

SCD access is dependent on how socioeconomic and health system characteristics interplay. Therefore, from a health system perspective, access to SCD care is characterized by four interrelated dimensions: availability, affordability, acceptability, and quality of care, which mirror established frameworks for access to health services.

2.4 Care Pathways and Healthcare Utilization

Access to healthcare can alter the way a person interprets their socio-economic situation as an influencer of health outcomes. Adequate access to the health system provides early diagnosis, regular follow-up visits, preventive health services, and adherence to medications that change the course of the disease.

2.5 Health Outcomes, Quality of Life, and Feedback Mechanisms

Patients with sickle cell disease may have poor health outcomes due to being both socioeconomically deprived and experiencing barriers to access to healthcare. While they physically experience many adverse effects from the disease, there are also numerous psychosocial impacts, such as chronic pain, social isolation, feelings of being alone, and a wide range of functional limitations. Figure 1 presents a visual synthesis of the conceptual framework guiding this review, illustrating the interactions between structural socioeconomic determinants, health system access dimensions, care pathways, and health outcomes in SCD.

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Figure 1: Conceptual framework illustrating socioeconomic and health system influences on SCD outcomes

3. Methods (Narrative Review Approach)

In this study, a narrative review method is used to explore the global evidence on socioeconomic inequalities as well as the health system in SCD. This kind of method is chosen because it enables the formation of a comprehensive, thematic exploration of how structural, social, and economic factors, such as poverty, education, and discrimination, interconnect to create disparities in care by investigating the existing research studies related to socioeconomic inequalities and health system access in SCD.

Search strategy

As a search strategy, the research studies are taken from different databases like Springer, IEEE, Google Scholar, and PubMed based on different keywords related to the review objective. Completely, 40 research studies are selected and reviewed to identify the significance of global evidence on socioeconomic inequalities as well as the health system in SCD. In this review, the articles are taken between the time periods of 2016 and 2026.

Other than the narrative approach, there is a need for a structured search strategy. The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) framework is used to provide a clear, visual representation of the search results, including the number of studies identified, screened, and excluded, allowing other researchers to replicate the review. Figure 2 explores the PRISMA framework of the review.



Figure 2: PRISMA framework of the review

Inclusion of key literature

In the inclusion criteria, the articles published between the time period of 2016 and 2026 are included. Articles that cover socioeconomic factors (such as income, education, employment, or social protection) and/or health system dimensions of access (availability, affordability, acceptability, and quality of care) in relation to SCD are included in this review.

Exclusion of key literature

Regarding exclusion criteria, the articles published before 2016 are not considered in this review. Articles concentrating exclusively on clinical interventions without reference to social or health system contexts are excluded. Articles that are not related to the socioeconomic factors (such as income, education, employment, or social protection) and/or health system dimensions of access (availability, affordability, acceptability, and quality of care) associated with the SCD are excluded.

Thematic Approach to Synthesis

A structured plan is employed to analyze the data qualitatively through narrative thematic synthesis. The included evidence-based studies are investigated in their entirety, with key findings extracted and categorized into recurring themes. The established access to care and social determinants frameworks provide guidance for determining the themes that emerge. The five major thematic areas identified are socioeconomic disparities, barriers in the health delivery system, the interaction of social and health delivery system factors, the impact of these factors on health outcomes and quality of life, and the response of policies and programming. The findings across the different regions and design types of studies are used to analyze similarities and differences, reveal gaps in the evidence, and identify future research areas. By utilizing this approach, a coherent synthesis of the differences in data is achieved, thereby better

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illustrating the structural causes of inequity in SCD care and outcomes.

4. Literature review

4.1. Socioeconomic Inequalities in SCD

There is a relation between socioeconomic inequalities in SCD and their ability to get quality medical care [5]. People with SCD tend to live in poverty, have lower levels of education, have less stable employment, and have inadequate health insurance, thereby discriminating against them regarding access to timely diagnosis [6]. In addition, socio-political conditions can create physical barriers, such as living a long distance from the nearest specialty clinic and a lack of financial resources to get to the clinic [7]. Socio-economic inequalities, including low income, limited education, and poor access to employment and social support, significantly worsen outcomes of individuals with SCD.

In the research study [8], the estimated life expectancy and income of patients with SCD compared with those without SCD were explored. In a 1-way sensitivity analysis, personal income and mortality rates stood out as important factors associated with the total lost lifetime income. There was a need to develop disease-modifying therapies that could improve the underlying morbidity and mortality of individuals with SCD. Like Income and mortality rates, education and poverty were also explored in the study [9]. The etiology of severe anemia in children with sickle cell anemia in Nigeria was likely to be multifactorial, which interplayed between an individual's disease severity and other socio-economic factors related to poverty. Similar to the study [8], the socio-economic burden, such as the income of SCD on families attending sickle cell clinic, was explored in the study [10]. Findings supported prioritizing affordable healthcare access for families affected by SCD to alleviate the burdens that they faced. Like the study [9], the socio-environmental exposures and health outcomes among persons with SCD were investigated in the study [11]. Persons in areas with higher annual rainfall, higher mean temperatures, and living farther from factories had less painful crises and respiratory events.

Like income and poverty, health literacy in SCD is also one of the socioeconomic inequalities to understand, process, and manage this complex and chronic condition. Study [12] also demonstrated the

high prevalence of inadequate Health literacy among adolescent patients. This finding not only highlighted the potential value of implementing Health literacy universal precautions but also suggested that patients were likely to require extra support during the period of transition. Similar to income, poverty, and Health literacy, the Mental Health, Education, Employment, and Pain in SCD were explored in the study [13]. Findings of the study [13] suggested that pain interventions could not ignore screening for depression and other mental health challenges among patients with SCD. Also, in the study [14], the disease knowledge and health literacy in parents of children with SCD were explored. From the results of [14], it was found that the employment status had also been shown to be associated with hospital admissions in patients with SCD. A key limitation of the study [14] was the sample bias arising from the use of a convenience sample. Additionally, the health literacy and disease knowledge in adolescents and young adults with SCD in Benin were explored in the study [15]. It was found that the disease knowledge was significantly associated with painful episodes after adjusting for both socio-demographic characteristics and clinical characteristics.

Similar to income, poverty, and health literacy, the impact of SCD on the employment situation of people was explored in the study [16]. The findings showed that the sample was more sensitive to the employment item than the depression item in the Emergency Department-Sickle Cell Assessment of Needs and Strengths (ED-SCANS) interview. In the research studies [17] & [18], the burden of disease, treatment utilization, and the impact on education and employment in patients with SCD and the burden of employment loss and absenteeism in adults and caregivers of children with sickle cell disease were explained. When compared with other participating countries in SWAY, more patients from the USA reported a high impact of SCD on various aspects of their work life and career progression, supporting multiple USA-based studies that noted the substantial negative impact of SCD on employment [17]. Employment loss and absenteeism due to hospitalization represented prevalent issues in families affected by SCD, which led to significant financial losses of >\$2 million annually [18]. Finally, the Health-related quality of life of adolescents with sickle cell disease in sub-Saharan Africa was explored in the study [19]. It was found that adolescents with SCD had low HRQoL as assessed by participants. The

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mean physical, emotional, school, and psychosocial functioning were below the cut-off as assessed by adolescents with SCD. Further, the research studies related to socioeconomic inequalities in SCD are explored in Table 1.

Table 1: Research studies related to socioeconomic inequalities in SCD

Study Type	Mean Age	Gender		Total Participants	Findings					Challenges	Ref
		Male	Female		Mean	Significance (p) (No unit)	Income	Literacy rate	Employment rate		
Investigation study	< 15 years	998	652	8738 (95% uncertainty level)	1.14	NI	\$135850 for SCD and \$1923000 without SCD	NI	44%	Limited availability of data.	[8]
Evidence-based study	5 to 12 years	NI	51.96%	488	1.70%	0.285	Low income	NI	88.30%	Living in low-resource settings had not been fully checked.	[9]
Research study	15.1-18.6 years.	15.10%	84%	1369	NI	0.01	30,000 Naira or less	85.10%	27.66%	Studies did not adequately address the mental and financial impact on patients.	[10]
Evidence-based study	5 to 18 years	4129	4373	8394	0.5%±0.3%	<0.001	NI	82.06%	NI	Milder genotype did not make the effort to attend for medicines.	[11]
Research study	≥16 years	NI	NI	45	4.20%	<0.001	\$49-463	14%	17.80%	The purpose and importance of ongoing therapy were not taught routinely.	[12]
Observational Study	14-8 years	992	1272	2284	7.90%	<0.001	Less than \$25000	NI	95%	Employment status was no longer significant.	[13]
Investigation study	15 to 45 years	Male	92.50%	117	5.90%	0.04%	NI	3.59%	22.20%	Inconsistent medical records.	[14]
Research study	14 to 25 years	66	65	131	10%	0.195	NI	32%	57%	No associations were found among sex, parental education levels, etc.	[15]
Observational Study	≥21 years	55	45	95	27.60%	0.179	NI	NI	4.73%	It was not possible to incorporate comprehensive information and accurate.	[16]

The sample sizes in the studies listed in Table 1 included participants from pediatric and young adult groups, and distinct sample sizes showed significant variability in study size. Some studies had a greater representation of females than males; however, gender representation was not consistent across studies. All studies provided evidence of socio-economic inequality for the sample of individuals with SCD using socio-economic indicators, including low income, low level of literacy, and low levels of workplace participation. Many of the studies identified statistically significant ($p < 0.05$) associations between socio-economic status and health outcomes, indicating that social determinants had an impact on disease management and access to health care. The majority of studies also identified important limitations, such as insufficient access to relevant data sources, incomplete medical records, a lack of appropriate diagnostic tools, and inadequate

assessment of the mental and financial burdens associated with SCD.

4.2. Health System Barriers to Access

Access to quality care for people who have SCD is significantly restricted by barriers related to healthcare systems, especially in regard to availability, affordability, and acceptability of services [20]. Specialized services for SCD are often found in short supply and tend to be clustered in large urban tertiary hospitals across many regions. Creating barriers to financial and other areas also reduces accessibility and acceptance of care. While many people are able to access high-quality and affordable care, they are confronted with challenges in being able to purchase goods and services that contribute to their ability to remain healthy, such as the costs associated with recurrent hospitalizations, long-term medications, laboratory monitoring, and indirect costs associated with obtaining services. These barriers combine to produce inequities for people with SCD, which impacts their ability to receive timely, comprehensive, and high-quality healthcare services.

In the research study [21], the perspectives of individuals with SCD on barriers to care were explored. Interviews were transcribed and coded, exploring themes around barriers to care. Socio-environmental/organizational level barriers included limited transportation, lack of insurance, administrative barriers, poor care coordination, and reduced access to care due to limited clinic availability. Barriers to high-quality care in SCD were investigated in the study [22]. Parents who reported more barriers were least likely to perceive their care as accessible, comprehensive, and coordinated [22]. Similar to the barriers discussed in the research studies [21] & [22], the Barriers to sickle cell disease care as a biopsychosocial analysis mapped to the standards of care guidelines by the Sickle Pan-African Research Consortium were explored in the study [23]. Most barriers clustered around three Sickle Pan-African Research Consortium (SPARCo) Standards of Care (SoC) domains: health maintenance and preventive therapy, management of acute complications, and specialised protocols. Suggested priorities included integrating SCD care into existing vertical programmes and co-designing pediatric-to-adult care transition models with patient support groups. In the study [24], the Barriers to Healthcare for SCD Patients in the Democratic Republic were

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explored. Concerning the barriers related to the perceptions and the evaluation of the supply of the health services and their affordability, most of the respondents declared that the cost of care related to sickle cell anemia was unaffordable.

Further, in the study [25], the Universal Health Coverage (UHC) among Jamaicans with SCD was investigated. Most SCD subjects reported no expense with public hospitalizations; however, approximately one in five reported OPPs. Efforts were needed to increase the availability of subsidized items and the use of drug-subsidy cards and to improve UHC. The major limitation of this study was that access to bills was not given. Also, in the studies [26] & [27], the acceptability and feasibility of a disease-specific patient portal in adolescents with SCD and the acceptability of Newborn Screening for SCD in Nigeria were explored. The results of the study [26] demonstrated the acceptability, feasibility, and some initial efficacy of an Electronic Medical Record (EMR)-based disease-specific healthcare portal designed for Adolescents and Young Adults (AYAs) with SCD. Analysis of the study [27] indicated that there was a good acceptability of NBS across Nigeria. The main barriers were likely to be financial and practical, rather than social or cultural. Study [28] improved access to healthcare for pediatric sickle cell disease patients through a qualitative study of healthcare professionals' views. Converged into six key themes, the analysis shed light on barriers and potential solutions to accessing healthcare, which might serve as a clinically useful resource to improve care for patients with SCD [28]. Further, the important aspects of research articles associated with the health system barriers to accessing the SCD are shown in Table 2.

Table 2: Important aspects of research articles associated with the health system barriers to access to the SCD

Study Type	Patient Group	Gender		Region	Duration	Total Patients	N% (phenotype)	Barriers			Challenges	Ref
		Male	Female					Availability and distribution of services	Affordability and financial protection	Acceptability and quality of care		
Research Study	Children and Adults	84	121	Nil	March 2018 to June 2018	208 individuals	20.20%	53.60%	13.90%	14.50%	The difference in proportions among sites for the majority of barriers was narrow.	[21]
Experimental research study	Children	19	19	Nil	12 months	38	3.2%	63%	Nil	68%	Difficulties were reported in the dimensions of access.	[22]
Observational study	Children and Adults	No Human research	Nil	Nil	Nil	No Human research participants	Nil	Biological barriers to care were reported in 14.8% of studies, social barriers in 85.2%, psychological barriers in 40.7%, and operational issues in 74.1%.	Nil	Nil	Implementation in African settings was constrained by the context-specific health system.	[23]
Experimental research study	Not specified	Not specified	Nil	Republic of Congo	Nil	158 SCD Patients	Nil	Nil	Unaffordable: 93.6% (Affordable: 100-93.6%)=6%	22.60%	Few studies in SSA had examined various barriers.	[24]
Research Study	Adults	45.60%	51.50%	Jamaica	12 months	103 patients	11.70%	Nil	25.50%	6.90%	The impact of transportation access and costs might be significant.	[25]
Observational study	Adults	45.5	54.5	Nil	3 months	61 participants	18.82%	Nil	Nil	90.12%	Did not significantly predict improved medical decision-making.	[26]
Experimental research study	Adults	671	604	Nigeria	April 2014 to July 2014	1,119 participants	Nil	Nil	Nil	86.10%	The level of support required matched with action through bringing the screening closer to home.	[27]

From Table 2, it was found that diverse studies examined barriers, challenges, and access dimensions affecting individuals with SCD across different populations and regions. The availability barrier alone accounted for 20.2% of respondents in the study [21]. There were also significant differences with respect to the affordability barrier across multiple backgrounds. In the Republic of Congo, 93.6% of patients cited unaffordability as their primary reason for not receiving care, and thus, they had very limited financial resources and poor financial protection. The acceptability and quality barrier also varied quite a lot across studies. Some studies [21] & [25] cited a low percentage of the total response (6.9–14.5%), while others recognized high levels (90.3%) for reporting reasons related to the quality of care provided. Social and operational barriers were quite prevalent in the observational evidence. In general, greater than 85%

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of studies included social barriers, and greater than 70% included operational barriers.

4.3. Interaction between Social and Health System Factors

The social and health system components associated with SCD interact to produce substantial inequalities. For instance, the socioeconomic detriment associated with poverty, inadequate housing, and low educational attainment enhances the severity of pain experienced by those with SCD as well as their use of emergency rooms (ER) for treatment, increasing the overall severity of their disease.

In the research study [29], the Social Determinants of Neurocognitive and Academic Performance in SCD were investigated. Stepwise multivariate models demonstrated that patients with low social vulnerability (i.e., high SES) at the neighborhood level displayed intelligence. The study identified patients with SCD at higher risk of poor academic performance based on SES. Interventions addressing academic difficulties should be offered to all children with SCD, but should be emergently offered to this sub-population. However, in the study [30], the Social and Psychological Factors Associated with Health Care Transition for Young Adults Living with SCD were explored. From the findings, it was found that social and psychological factors and self-management experiences influence the health care transition.

4.4. Consequences for Health Outcomes and Quality of Life

The impact of SCD on health-related quality of life (HRQoL) is profound and multidimensional. Ongoing pain, fatigue, and restricted physical ability have a major influence on how people with SCD can carry out their daily lives, gain an education, and work [31]. Children with SCD often experience delays in their growth, more frequent visits to school, and increased levels of stress. Adults with SCD issues regarding their ability to produce income, have financial security, and socially interact with those around them. Due to pain events being unpredictable, there is increased anxiety about the future and uncertainty related to present activities and future planning [32].

Additionally, in the studies [33] & [34], the qualitative assessment of health-related quality of life impacts associated with SCD in the United States and United Kingdom and Health-related quality of life and

economic impacts in adults with sickle cell disease with recurrent vaso-occlusive crises were explored. Qualitative analysis demonstrated the negative impacts of SCD on HRQoL in physical health, social and family life, work, and education, and identified unmet needs in individuals with SCD [33]. Finally, in the study [34], the participants also reported increased pain, stiffness, and emotional impacts compared to a reference sample of adults with SCD on the ASCQ-Me, and most of the participants (60%) reported moderate to extreme pain/discomfort on the NRS of pain.

4.5. Policy and Programmatic Implications

Policy and programmatic responses to SCD must prioritize health system strengthening and equity-oriented interventions to address persistent disparities in access, quality, and outcomes. Health systems must support the development of primary care services with SCD component programs (newborn screening and early diagnosis) and access to a timely and reliable supply of essential medications and trained provider capacity to provide SCD services (through specialised education/training) [35]. Financial solutions must be equally responsive through equitable funding sources, such as universal health coverage and financial risk protection, to eliminate the majority of economic strains on affected individuals and families.

The research study [36] provided the policy justification to broadly implement newborn screening programs across the US through newborn screening processes; thus, children with sickle cell disease could obtain the anticipatory care they needed. Additionally, in the study [37], the Newborn Screening Programs and SCD were explored. NBS programs performed important public health roles that complemented and enhanced clinical services. Nationwide efforts were needed to enable NBS programs to strengthen population-based functions that were essential to ensuring quality of care for the entire population of children and families affected by SCD. In the research study [38], the Perspectives on Building Sustainable Newborn Screening (NBS) Programs for SCD were investigated. The findings had demonstrated both the opportunities and areas that addressed the implementation and sustainability of the services in low-resource settings. Finally, in the research studies [39] & [40], the Universal Screening for Social Determinants of Health in Pediatric SCD and Community engagement to inform the development of a sickle cell counselor training were explored. 39% of families enrolled in a community program at their 12-

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month follow-up [39]. The counselor training program was intended to provide accurate and non-directive information for young people who might be tested for SCD or SCT [40]. A majority of the participants were female, although the faculty did not observe any differential contribution, recommendations, or insights based on gender. Table 3 explores the research articles associated with the significant aspects of policy and programs of SCD.

Table 3: Research articles associated with the significant aspects of policy and programs of SCD

Study type	Region	Target patients	Findings					Challenges	Ref	
			Policies		Programmatic implications					
			Health Policy	Social intervention program	Financial protection policy	Newborn Screening (NBS)	Community Engagement Programs			
Research study	Not specified	Children	✓	✓	✓	✓	✗	✗	The heel prick test was insufficient to compare an efficacious newborn screening program.	[36]
Research study	Western Kenya	Children	✓	✗	✗	✓	✗	✗	HCPs were not equipped with the basic knowledge and skills on SCD.	[37]
Observational study		Children	✗	✓	✗	✗	✗	✗	Acceptability was not considered as a challenge.	[38]
Observational study	Northeast US	Children	✓	✗	✗	✗	✓	✗	There was a little exploration of the psychosocial impact on the family.	[39]
Research study	Ghana	Children	✓	✓	✗	✗	✗	✓	The primary care clinic or outpatient service was not characterized.	[40]

✓ : Included and ✗ : not included

implementation of newborn screening (NBS) programs. An observational study [38] found that while social intervention programs provided an important resource for the management of SCD, the level of engagement between social intervention programs and the formal health policy framework, the availability of financial protection, and the availability of NBS programs was limited. Although studies indicated that a lack of acceptability was a significant barrier, differences in community perceptions might contribute to variability in the degree of support for SCD. In the Northeast United States [39], well-established health policy frameworks existed to support SCD care, and community-based support programs were implemented; however, the psychosocial impact of SCD on families was not given adequate consideration.

5. Research gaps and future directions

Although the impact of socioeconomic inequalities on people with Sickle Cell Disease (SCD) is becoming more widely recognized, gaps still exist in the available evidence. For example, there is a lack of longitudinal or multicountry comparative studies examining the effects of socioeconomic factors on SCD outcomes over time and across different types of healthcare systems. Most current research is cross-sectional or one country, meaning there is limited capacity to infer causal patterns and generalise findings globally. In addition to the lack of comparative longitudinal studies, there is also a lack of data on marginalized and rural SCD populations; the majority of published studies are based in urban tertiary care facilities. This creates an incomplete picture of the inequities faced by marginalized and rural people with SCD in accessing healthcare and the extent to which they are experiencing a lack of access. The absence of evidence of the burden of out-of-pocket expenses, catastrophic health expenses, or lost productivity due to SCD also limits the ability to develop equitable financing and social protection policies. Also, evaluations of health system interventions designed to reduce inequities in SCD care are scarce. There is a need for implementation research that assesses the effectiveness, scalability, and sustainability of models, such as community-based care, telemedicine, task shifting, and financial protection mechanisms. Future research should address these gaps by prioritizing longitudinal, mixed-methods, and participatory approaches, building comprehensive, disaggregated datasets, and generating evidence that directly informs policy and practice.

A review of selected studies in various regions indicated that there was a disconnection between the development and implementation of health policies and programs designed to improve care for sickle cell patients. Many of the studies also indicated that there were still major gaps in service delivery and the overall capacity of health systems to provide care for sickle cell patients. Most studies emphasized the need for health policy frameworks to support the

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6. CONCLUSION

In this narrative review, the socioeconomic inequalities and health system access in SCD were explored via distinct research studies. The literature review revealed several important issues. From the discussed research studies, it was found that the individuals who resided in low-income homes, rural areas, and marginalized communities faced much greater disease burden, more complications, and an inferior quality of life than people from affluent communities. These findings were important because they were related to health equity and future policy development. The evidence indicated that unequal access to SCD care was not only a clinical issue but also a systemic and social issue. Removing socioeconomic barriers and healthcare systemic barriers helped to improve survival rates, decrease the incidence of preventable complications, enhance access to universal healthcare coverage, and promote social justice for people with SCD. This review had many limitations. Being a narrative review, it had potential bias in the literature searched and lacked the quantitative synthesis of a systematic review or meta-analysis. Comparability limitations existed as a result of high variability in study designs, outcome measures, and regions analyzed. Lastly, there was little available data from low-resource settings or rural areas. Based on these findings, future research will prioritize longitudinal and comparative studies, generate disaggregated data on vulnerable populations, and evaluate equity-focused health system interventions.

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