

# Trends In Hospitalization, Treatment Costs, And Length of Stay for Sickle Cell Disease Patients in the United States: A Comprehensive Analysis

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#### **Abstract**

Sickle cell disease is a major health concern in the United States, particularly among the Black population of African origin. It significantly impacts both patients and health facilities. This study, therefore, leverages a trend analysis of African American hospitalization rates, treatment costs, and lengths of stay from 1998 to 2020. The study used a quantitative analysis technique to assess the secondary datasets sourced from the National Hospital Discharge Surveys databases. The study found that the average cost of treatment for both adult and children SCD patients showed a consistent linear increase from 1998 to 2020. Conversely, the length of hospital stays exhibited a decreasing linear trend during the same period. However, the hospitalization rates did not display any linear trend. This evidence supports the view that SCD remains a significant source of ongoing economic costs and calls for specific actions to increase the availability of effective SCD care, optimize disease outcomes, and reduce health risks among those affected.

**Keywords**: Sickle Cell Disease, Healthcare Utilization, Hospitalization Trends, Treatment Costs, Length of Stay, African Americans, Health Disparities, Management of Disease, Health Insurance, Red Blood Cell, Policy.

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### Introduction

Sickle cell disease also known as SCD is best described as a chronic hereditary ailment that mainly impacts people of African origin usually those who live in the United States of America. This multisystem disorder is associated with defective red blood cells, which has the sickle shape; its complications may include pain crises, stroke, acute chest syndrome, and also organ damage (Kato et al., 2018). Despite recent improvements made in the care and control of the disease, SCD is still a major public crisis not only in Africa, but for the black population in general. The effects of SCD on recipients, their families, caregivers, and the healthcare system are enormous. Hospitalized patients develop several complications and many of them are prone to frequent readmissions, lengthy hospital stays, and expensive treatments that could cause substantial financial pressures (Brousseau et al., 2010). Moreover, SCD patients have poor quality of life and shorter life spans than the normal population, usually they die about 20-30 years younger than the normal population (Hassell, 2010).

It is essential to focus on the significant disparities and inequalities observed in SCD patients' health and ensure their equal access to valuable treatment and resources. Despite this however, there is a need for policy makers, health care providers, advocates and the public in general to have an all-inclusive understanding of hospitalization rates, costs and duration in order to guide policy formulation and resource mobilization for interventions. The objective of this study is to provide an analytical review of the trends in hospitalization rates, costs of treatment, and lengths of hospitalization for African Americans with SCD in the United States over the period 1998–2020. Furthermore, the study seeks to compare and understand the impact of the following factors; age, gender, race, insurance type, and type of SCD in its relation to the mentioned outcomes. Thus, through identifying these trends and relevant factors, this study aims to offer recommendations to targeted population, policy makers, healthcare personnel, and other interested stakeholders to inspire the creation of more effective intervention and policies addressing the enduring barriers of SCD patients' health and health care equity. It also aims to examine the trend and project long-term hospitalization rates, treatment costs, and length of stay for patients with SCD. In assessing the trends from 1998 to 2020, the research will establish a pattern of fluctuation and probable future directions in SCD-related healthcare use and costs. Such trend analysis shall yield valuable insights into the changing management landscape of SCD and its economic impact over time. The identification of these trends and their projection over history is expected to allow for data-driven recommendations, such as those resulting from this study, to be made to policymakers, health providers, and other stakeholders. This kind of insight will help in strategic planning, resource allocation, and the development of targeted interventions that



aim at meeting the changing challenges in SCD care for increased effectiveness and efficiency of delivered healthcare to this category of patients.

## **Literature Review**

Sickle cell disease has been acknowledged as a public health issue of concern, more so among the African American people (Hassell, 2010). Several research have demonstrated how SCD affects health care access, treatment charges, and lifestyle amongst others. The hospitalization rates for SCD patients have also been seen to be significantly higher as compared to non-sickle cell population (Okam et al., 2014). The causes of frequent hospitalization include: pain crisis, acute complications and other complications related to SCD (Brousseau et al., 2010). The study on hospitalization rates revealed that insurance status and ability to get adequate care are some aspects that can predict hospitalization rates (Davis et al., 1997). The costs in relation to SCD are considerable, and it has been projected that patients affected by SCD are likely to spend more than one million US dollars on healthcare by the time they reach 60 years of age. These costs arise from repeated hospitalizations, emergency room visits, specialized treatment and care (Bahr 2015). Understanding the availability and the affordability of care and treatment for patients with sickle cell disease is crucial. SCD patients of low-income backgrounds or those under-represented ethnic backgrounds faces challenges related to accessing affordable care (Lee et al., 2019). Access to having appropriate health care services, including medications specialized treatments, and supportive care influencing the management of SCD is very important.

It has been noted that days hospitalized for SCD significantly contribute to the rise in the global health care costs (Ye et al., 2016). There are complications that arise during treatment such as: the inability to manage pain effectively, and restricted access to quality care led to extended hospital stays (Brousseau et al., 2010). Socioeconomic factors as it relates to insurance and the availability of specialized care have also been looked at in relation to the duration of stay in hospitals (Davis et al., 1997). Nevertheless, these research works help to establish the barriers to medication adherence experienced by patients with SCD. However, there is a lack of comprehensive studies that assess the trends in hospitalization rates, associated costs, length of hospital stay, and other factors in the long term. Such analyses may help in designing specific strategies and policies for readdressing continued health inequalities with reference to this susceptible population.

## **Sickle Cell Disease Funding**

Sickle Cell Disease (SCD) faces chronic underfunding and minimal awareness, exacerbated by systematic racial disparities compared to conditions like cystic fibrosis and hemophilia. This disparity has hindered advancements in disease understanding, treatment development, and quality of life improvements for SCD patients (Steinberg et al., 2009). Despite efforts from organizations like the American Society of Hematology and the Sickle Cell Disease Association of America, funding for SCD research remains disproportionately low compared to diseases with predominantly non-minority populations (Treadwell et al., 2019).

The National Institutes of Health (NIH), primarily through the National Heart, Lung, and Blood Institute and the National Institute of Diabetes and Digestive and Kidney Diseases, plays a crucial role in funding SCD research (NIH, 2023). However, funding levels per patient are significantly lower for SCD compared to diseases like cystic fibrosis, despite SCD being more prevalent. This disparity affects research progress, limits innovative treatments, and hampers efforts to recruit specialized healthcare professionals. Recent initiatives, such as a \$7.7 million NIH grant to Dr. Julie Kanter at the University of Alabama at Birmingham, aim to address barriers to care and improve access to disease-specific screenings and treatments for underserved SCD populations (Kanter Receives \$7.7 Million Grant from the NIH to Advance Sickle Cell Disease Research, n.d.). This funding is particularly crucial for adults and those in rural or socioeconomically challenged areas who lack access to specialized care.

It is important to note that while some progress is being made through targeted research grants, the overall funding landscape for SCD remains insufficient. Addressing this disparity requires sustained advocacy, increased public awareness, and targeted funding allocations that reflect the true burden and needs of the SCD community.

#### Trend of Hospitalization and Healthcare Cost for SCD Patients

Three themes can be deduced from the literature reviewed regarding sickle cell disease: hospitalization patterns, health care costs, and factors influencing outcomes. According to research on the pattern of hospitalization, patients with SCD get hospitalized more often compared to the general population (Okam et al.,



2014). This might be attributed to recurrent hospitalization because of pain crisis, acute complications, and other SCD-related problems (Brousseau et al., 2010). The long-term trend of this pattern was important in the process of understanding how SCD management needs and healthcare resource uses have evolved over time. Healthcare costs for SCD have only recently received a large amount of attention. It was estimated that, by the age of 60 years, SCD patients could have health costs running into more than one million dollars, underpinned by a high rate of hospitalization, emergency treats, and complex treatments in this illness. Long-term cost trend analysis brings out insights into the economic burden arising from SCD and helps in the forecasting of future healthcare expenditure.

Different studies have highlighted the socioeconomic status of patients, insurance coverage, and access to specialized care as major determinants for inefficacy in patient outcome.

This goes along with determining the rate of hospitalization, length of stay in the hospital, and type of management that is utilized for the illness (Davis et al., 1997; Lee et al., 2019). Long-term trend analysis will be done for the evaluation of disparities which remain more persistent and will provide the areas needed for intervention for these factors. While these themes have been explored in studies on an individual level, an analyzing gap exists pertaining to long-term trends of hospitalization rates and costs, underpinning factors in an integrated manner. Such analyses are very important in developing appropriate health inequity targeted strategies for SCD patients over time. The current study filled this gap by taking a careful look at the trends from 1998 to 2020 in in-patient care for SCD, in a bid to derive useful insights for policy development and healthcare planning.

## Methodology

This paper adopted a quantitative analysis of secondary datasets to establish time trends in hospitalizations, costs, and hospitalizations days for SCD among African American within the United States between 1998 and 2020. The study retrieved data from the National Hospital Discharge Surveys archives as the main source of secondary data. Hospitalization rates, was captured as the SCD case fatality rate per number of SCD related hospitalization divided by 100,000 African American populations. Also, the treatment costs, was measured as the anticipated average costs when an SCD patient is hospitalized, cost of treatments that include direct medical expenses. Above all, the variable length of hospital stay, was also captured in the dataset as the average length of stay for all admissions that are directly related to SCD.

This study consists of three separate models take into accounts the trend equation for SCD patients' hospitalization rates, length of stay and hospital treatment costs for the period between 1998 and 2020. If that is the case, then it might be appropriate to fit a sloping line rather than a horizontal line to the entire series. Therefore, the general trend model becomes: Yi = a + bX + e, where (Yi = HPR, LOS, & HTC). As a result, the specific trend line equations or models are given as below:

HPR = a + bTime + e (1	)
LOS= a + bTime + e. (2)	)
HTC= a + bTime + e. (3)	(

Where, HPR=Hospitalization rates, LOS= Length of Stay, HTC= Hospital Treatment Cost, and X= time index, a =constant trend, and b=slope of the trend line or equation. This equation is a linear trend model, also known as a trend-line model (Y= a + bX). In fact, trend-line model is a special case of a simple regression model in which the independent variable is just a time index variable, i.e., 1, 2, 3 ... or 1998, 1999, 2000, ...... 2020 or some other equally spaced sequence of numbers. When it is estimated by regression, the trend line is the unique line that minimizes the sum of squared deviations from the data and measured in the vertical direction.

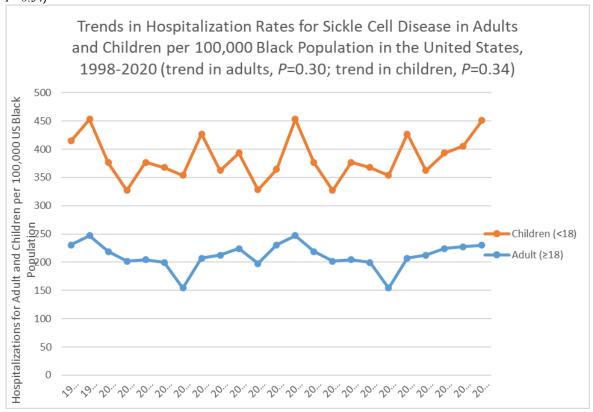


#### **Results and Data Presentation**

#### Figure 1

Trends in Hospitalization Rates for Sickle Cell Disease per 100,000 Black Population in the U.S., 1998-2020 (Adults: P=0.30; Children:

P=0.34)



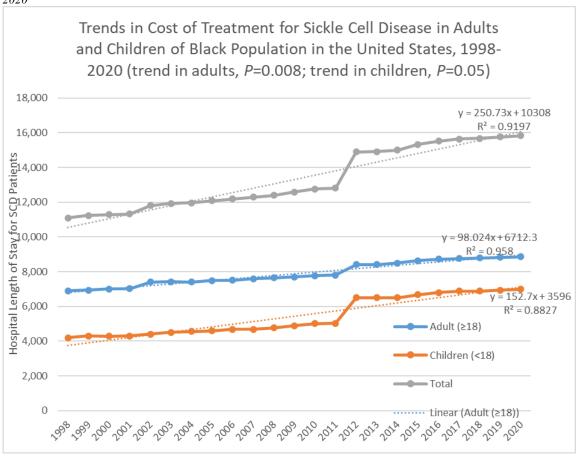
Source: Excel Output

Figure 1 illustrates the trends in hospitalization rates for sickle cell disease (SCD) among adults and children per 100,000 Black population in the United States from 1998 to 2020. The data in Figure 1, indicates that hospitalization rates for both adults and children with SCD do not show a clear linear increase or decrease over time. Instead, the trends are best represented by a moving average over two periods from 1998 to 2020, as evidenced by a very low linear trend R-squared value (R<sup>2</sup>=0.0005). The analysis in Figure 1 further confirms that there is no significant constant trend (linear, exponential, polynomial, etc.) in the hospitalization rates for SCD during this period. The moving average trend emerges as the most suitable fit for the dataset from 1998 to 2020 (refer to Figure 1).

Figure 2 illustrates the trends in treatment costs for Sickle Cell Disease (SCD) in both adults and children from 1998 to 2020. The figure reveals a consistent linear increase in the average cost of treatment for SCD patients during this period. The linear trend is supported by high R-squared values, indicating a strong fit: R2 = 0.958 for adults and R2 = 0.883 for children. The overall trend for all SCD patients also shows a significant linear increase, with an R-squared value of 0.958. Therefore, the most accurate representation of the average hospital treatment costs for SCD patients from 1998 to 2020 is a linear trend, as detailed in Figure 2.



**Figure 2** Trends in Cost of Treatment or Hospital Treatment Cost (HTC) for Sickle Cell Disease in Adults and Children of Black Population in the United States, 1998-2020



Source: Excel Output

The trends in the cost of treatment or hospital treatment cost for SCD in adults and children has increased overtime because of the rising healthcare costs in the United States for SCD patients. According to Alker, Kenney and Rosenbaum (2020), the general trends in the rising healthcare costs seems to have contributed to the increased in cost of treatment and general hospital expenses for SCD patients. Again, the Center for Medicare and Medicaid Services (2020) also argued in the literature that the socioeconomic disparities which include income level, insurance coverage and access to healthcare services have positively impacted the treatment costs for SCD patients in both adults and children. Above all, the increasing trends in the cost of treatment for SCD in adults and children in the Black population in the United States from 1998-2020 shows the economic impact of the disease on the SCD patients which changes the healthcare utilization patterns.



Figure 3
Trends in Hospital Length of Stay (LOS) for Sickle Cell Disease in Adults and Children of Black Population in the United States, 1998-2020

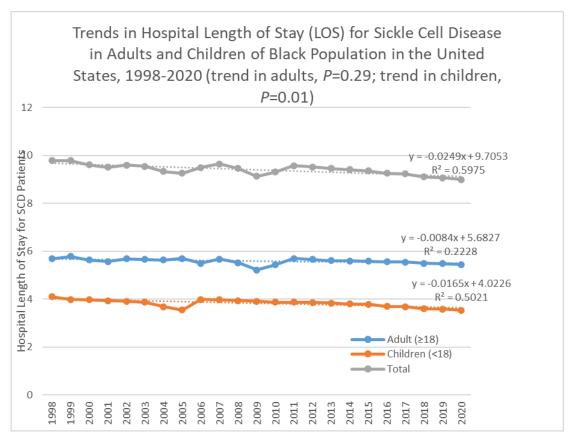


Figure 3 examines the trends in length of hospital stay for sickle cell disease (SCD) among adults and children, detailing the average number of days patients spent in the hospital per admission from 1998 to 2020. The analysis in Figure 3 indicates that both adults and children with SCD experienced a consistent decrease in their length of hospital stay over this period, as evidenced by significant linear trend R-squared values (Adults:  $R^2$ =0.266, Children:  $R^2$ =0.502). Additionally, when considering the combined dataset (total), the trend remains consistently linear with an R-squared value of 0.5975, further supporting this observation. Hence, the most suitable trend identified for the dataset from 1998 to 2020 is a linear decrease in hospital stay duration for SCD patients (refer to Figure 3 for more details).

#### Discussion

The findings from this study provide a comprehensive overview of the trends in hospitalization rates, treatment costs, and length of stay among individuals with sickle cell disease (SCD) in the United States over the past two decades. The results underscore the substantial economic burden associated with SCD and emphasize critical areas for improvement in care delivery for this vulnerable population. Notably, the study identifies a persistent lack of a linear relationship in hospitalization rates among SCD patients from 1998 to 2020, with rates remaining consistently high throughout this period. Previous research has consistently highlighted that individuals with SCD face significantly higher risks of hospitalization compared to the general population (Okam et al., 2014; Brousseau et al., 2010). Factors contributing to these high rates include challenges in disease management, disparities in access to integrated care, and variations in socioeconomic status.

The study also reveals a concerning lifelong increase in treatment costs for both adults and children with SCD, indicating a growing economic burden over time. This trend aligns with previous studies that have documented substantial lifetime healthcare costs associated with SCD (Bahr, 2015). Factors contributing to



rising costs include the development of expensive treatments, increased utilization of healthcare services, and the intersection of SCD with other health conditions, leading to additional financial burdens.

Regarding hospital stays, the study suggests a gradual worsening in the management and treatment progress of SCD over the years, as evidenced by trends in length of hospital stay. Possible factors influencing these trends include improved patient awareness, better continuity of care, and the implementation of best practices in SCD management (Brousseau et al., 2010). However, it is crucial to note that while early hospital discharge may help mitigate costs, it should not compromise patient care or lead to premature discharge, which can result in adverse outcomes and higher risks of readmission for complications.

Demographic and clinical predictors further illuminate disparities in hospitalization rates, treatment costs, and length of stay among SCD patients. Younger patients, particularly those under 18, often experience higher rates and costs, reflecting strategies tailored to pediatric SCD management that consider developmental stages, family dynamics, and the availability of specialized healthcare services (Brousseau et al., 2010). Moreover, disparities related to insurance type highlight inequities in healthcare access and costs, with patients covered by Medicaid and Medicare—typically indicating lower socioeconomic status—experiencing higher incidence rates, charges, and longer hospital stays compared to those with private insurance (Davis et al., 1997; Lee et al., 2019).

The implications of these findings underscore the urgent need for sustained research efforts aimed at improving the quality of life for SCD patients and addressing healthcare disparities. Public health initiatives and healthcare policymakers must prioritize initiatives that enhance disease management frameworks, reduce barriers to care access, and promote patient education. Implementation of evidence-based guidelines and models of care tailored to SCD can optimize disease management, reduce hospitalizations, and improve treatment outcomes.

Furthermore, efforts to expand access to affordable health insurance options and targeted therapies are critical in alleviating the financial burden of SCD treatment, particularly among minority populations. These comprehensive approaches are essential for advancing health equity and ensuring that all individuals with SCD receive timely, effective, and equitable care.

## **Conclusion and Policy Implications**

The analysis of trends in hospitalization rates, treatment costs, and length of stay for sickle cell disease (SCD) patients in the United States reveals significant challenges and disparities over the past two decades. Hospitalization rates have shown persistent high levels without a clear linear trend, indicating ongoing difficulties in disease management and access to integrated care. Treatment costs have steadily increased, reflecting the growing economic burden of SCD on patients, families, and healthcare systems. Meanwhile, the length of hospital stays has fluctuated, suggesting varied progress in managing SCD complications and optimizing patient care outcomes. Also, the financial cost of SCD remains high as evidenced by changes in length of stay, therefore calling for appropriate measures in providing health care, management and treatment of the disease as well as redressing the social determinants of health causing such condition. Understanding these challenges can help policymakers and other healthcare stakeholders to implement strategies that can enhance health equity among this vulnerable group of people (Crego et al. 2020). It is crucial that researchers, clinicians, policymakers, and other stakeholders targeted the realization of these findings into practice plans and policies that would enhance the quality of life of people with SCD. Supporting research, education, and broad-spectrum care interventions could open new opportunities in the effective treatment of SCD and also help to address the ongoing health inequalities affecting the African American population.

The following recommendations are thus made in view of the trends of hospitalization, treatment cost, and length of stay in SCD patients within an inpatient setting in the United States from 1998 to 2020. First, the trend of hospitalization rates is very complex, best fitted by a short-term moving average, which is indicative of the need for more targeted and therefore flexible health strategies. Policy decision-makers and health providers should work toward developing adaptive interventions that respond to short-term 'fluctuations' while handling the underlying determinants for these variations.

Secondly, strengthening community-based care programs in order to prevent hospitalization would follow through reasoning to stronger needed community programs and early intervention strategies. The increasing treatment cost for SCD patients calls for an incorporation of cost-containment measures and a more effective financial protection system. This calls upon healthcare institutions and policymakers to explore alternative ways of reducing the economic burden on SCD patients through price bargaining for drugs, increasing insurance coverage, and introducing cost-effective treatment protocols. Moreover, policies addressing



socioeconomic inequalities that increase treatment costs, including improving access to healthcare services among underserved populations, must be implemented (Lee.et al., 2019). The trend in the decline of hospital length of stay is also encouraging for both adult and pediatric SCD patients.

Best practices such as improved pain management, early intervention, and coverage of after-care-inpatient care, which have undoubtedly contributed to such trends, should continue to be developed and supported by healthcare providers. This will only be possible provided that shorter hospital stays do not come at the cost of downgraded care quality, readmissions, or failed transitions. Investments in transitional care programs and home-based support services must ensure the capability of patients to manage their condition effectively after discharging from hospitals. Finally, due to the complex interplay of factors influencing SCD care, very clear reasons should be made out for the requirement of a more comprehensive, integrated system of data collection and analysis. This national SCD registry has to be led by healthcare institutions and research bodies so as to provide real-time data about hospitalization rates, treatment costs, and patients' outcomes, opening up room for more responsive and evidence-based policy making and healthcare planning for SCD patients (Davis et al., 1997). These warnings should serve as the bedrock of work by stakeholders in improving care quality, reducing the economic burden of SCD, and improving quality of life for individuals living with this chronic disorder.

The analysis of SCD hospitalization rates, treatment costs, and hospital stay durations in the US from 1998 to 2020 has highlighted critical areas for future research and policy development. Hospitalization rates, characterized by short-term moving averages, necessitate adaptive healthcare strategies to address fluctuations effectively. Rising treatment costs underscore economic challenges for SCD patients and the healthcare system, emphasizing the need for robust cost-containment measures and improved financial support.

The trend towards shorter hospital stays for both adult and pediatric SCD patients suggests improvements in care protocols and management strategies, but careful monitoring is essential to maintain care quality and prevent increased readmissions. Overall, a more holistic, patient-centered approach is essential in managing SCD at medical and socioeconomic levels.

Limitations in this study, primarily focusing on national trends, warrant further research into regional or local variations in hospitalization rates, treatment costs, and lengths of stay. Future avenues include detailed state-level analyses to assess the impact of specific interventions or policy changes on SCD outcomes. Longitudinal studies tracking SCD patients over extended periods will provide valuable insights into long-term healthcare utilization and costs.

Qualitative research can complement these efforts by capturing nuanced experiences from individuals with SCD, their families, and healthcare providers, informing patient-centered interventions and policies. Establishing a nationwide SCD registry will facilitate evidence-based decision-making and improve responsiveness in SCD care. Addressing these gaps through targeted interventions will enhance the quality of care, reduce economic burdens, and ultimately improve the quality of life for individuals living with SCD. By integrating data-driven insights with patient-centered strategies, stakeholders can pave the way for more effective SCD management and improved health outcomes in the years to come.

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