SICKLE CELL DISEASE PARTNERSHIP

September 2023

Treating Sickle Cell Disease: An Opportunity to Concretely Improve Lives and Increase Health Equity

Overview

In recent years, policymakers have shown increased recognition of and interest in reducing health disparities and improving health equity. Today, too many Americans do not have equitable access to care and treatment due to outdated policies and biased practices.

> **"There would be no stronger affirmation of our national commitment to equity and racial justice than to prioritize assistance to those suffering from this disease."**
>
> Dr. Brett Giroir
> Former Assistant Secretary of Health, HHS

One of the greatest opportunities to concretely improve lives, reduce disparities, and improve health equity is to improve access to care and treatment for Americans with Sickle Cell Disease (SCD), a genetic blood disorder that predominantly impacts Black and Hispanic individuals. Americans with SCD often face barriers to care, including social drivers related to health (inadequate housing, transportation, or food insecurity). They may also face discrimination, stigma, or bias related to their race or medical condition in health care settings.

Policymakers interested in reducing health disparities and improving health equity should seek to help reduce the challenges experienced by Americans with SCD. Using policy levers available through Medicaid and other public programs, policymakers are uniquely positioned to make a significant, positive impact on the lives of thousands of Americans who suffer from SCD. Today, millions of Americans have a friend, neighbor, colleague, or family member who is one of the estimated 100,000 Americans living with SCD. When our fellow Americans have better access to care and treatment, improved outcomes, and stronger health, our communities are stronger, and our country is more resilient.

Overview of Sickle Cell Disease

SCD is a rare genetic blood disorder that impacts the shape of the hemoglobin protein in red blood cells. Normally, red blood cells are disc-shaped and flexible enough to move easily through the blood vessels; however, individuals with SCD have crescent- or "sickle"-shaped red blood cells due to the malformation of hemoglobin proteins.[i] The sickle-shaped red blood cells in individuals with SCD cannot move easily within the bloodstream and can block blood flow throughout the body.[ii]

The obstructed blood flow can lead to serious problems, including stroke, infections, and episodes of pain called pain crises.[iii] Unfortunately, in addition to these symptoms, SCD is typically a lifelong illness and the disease significantly shortens the average lifespan of patients. A 2019 study found that SCD patients live an average of 54 years, about 20 years shorter than those without SCD.[iv]

The prevalence of SCD in Black and Hispanic communities is notable. In the United States, an estimated 1 in 365 Black children and 1 in 340 Hispanic children are born with SCD.[v] Bone marrow transplants (often referred to as stem cell transplants) are currently the only cure for SCD; however, these are extremely risky procedures, and many individuals with SCD do not have a relative who is a close enough genetic match to be a donor. Most current treatment for SCD involves therapeutics that can reduce symptoms and prolong life. Other therapies, such as gene therapies, are additional potential treatments that are currently in development.[vi]

What is the relationship between Sickle Cell Disease and Health Equity?

The stigmatization and biases that SCD patients often experience may result in delays in their care and worse health outcomes. When SCD patients present to an emergency room or another clinical setting with complaints of pain, it is not uncommon for them to report discrimination and obstacles to care. In fact, a 2016 study examining bias against SCD patients found that 38 percent of participants reported some experience with discrimination in a health care setting.[vii]

Research studies have connected provider discrimination to negative impacts on care delivery. Two reports found that children[viii] and adults[ix] with SCD reporting to emergency departments with high pain intensity experienced greater delays in receiving analgesic medicine than other patients. In addition to these delays, an analysis of emergency department visits from 2003 to 2008 found that Black patients with SCD experienced 25 percent longer wait times to see a physician than the general patient sample.

Real Statements From Americans with SCD Speaking to Discrimination

"I've had providers who thought I was faking or exaggerating the pain I felt to get pain medications."

"I worry about being discriminated against because I have Sickle Cell."

"I'll have to wait several hours in the emergency room for any sort of pain relief."

Incidences of discrimination have a tangible negative impact on the health of Americans with SCD. Individuals with SCD that report disease and race-based discrimination in health care settings also report greater pain, pain severity, and pain burden.[x] Furthermore, individuals living with SCD who perceive stigma about their condition are at increased risk for negative self-evaluations, loss of self-esteem, anxiety, and social withdrawal that can negatively affect their health behavior and health status.[xi]

Medicaid Opportunities to Improve Outcomes for Sickle Cell Disease

Federal and state Medicaid policy levers are a meaningful way to drive interventions designed to improve health equity and reduce disparities. This is because research shows that about half of all Americans with SCD receive their health coverage through Medicaid.

Several states are creating a path forward in the health equity space for SCD patients by instituting new programs that directly target the disparities they face. A 2022 report from Sick Cells examined ongoing Medicaid initiatives to help address health disparities and health inequities within the healthcare system and ensure that individuals with SCD have access to relevant therapies, improved care, and other supports.[xii] The report identified steps that state Medicaid programs are taking to address health equity and social determinants of health. Data collection efforts are underway in California, which is establishing an SCD-specific reporting system. In Kentucky, the State Medicaid agency is beginning to examine prior authorization processes for SCD therapies. In New York, the state designated SCD patients as an at-risk population and implemented support for care transitions from pediatricians to adult providers.[xiii]

Moving Forward on Health Equity for SCD Patients

There is an opportunity and need for additional specific policies and approaches to improve health equity for individuals with SCD with Medicaid at the state and federal levels. Policymakers should further leverage the Medicaid program to implement other specific policies by supporting these pieces of legislation:

- ***The Sickle Cell Disease and Other Heritable Blood Disorders Research, Surveillance, Prevention, and Treatment Act of 2023*** **(118th, H.R. 3884 / S. 1852)** – bipartisan House & Senate legislation that reauthorizes the Health Resources and Services Administration (HRSA) Sickle Cell Disease Treatment Demonstration Program beyond FY 2023. This HRSA grant program aims to (1) increase the number of clinicians knowledgeable about SCD care; (2) improve the quality of care provided for SCD; (3) improve care coordination with other providers; and (4) develop best practices for coordination of services during pediatric to adult transition.
- ***The Sickle Cell Disease Comprehensive Care Act*** **(118th, H.R. 6216 / S. 3389)** – bipartisan House and Senate legislation that authorizes the federal government to establish a demonstration program in up to 10 states to provide comprehensive care to Americans with SCD receive health coverage through a state Medicaid program. The legislation would ensure such individuals in participating states have coordination of and access to clinical, mental health, and ancillary and support services they need because of their disease.
- ***The Sickle Cell Care Expansion Act*** **(118th, S. 1423, H.R. 3100)** – legislation to address provider shortage concerns in Medicaid by authorizing a scholarship and loan repayment program to incentivize medical physicians to enter into the field of SCD research and treatment. The bill would also award grants to health clinics, community organizations, and other local nonprofit organizations that work with individuals who have SCD to help improve their health literacy, equip them with information on health and community services related to SCD, and improve the care and treatment decision-making process related to the disease.

---

[i] https://www.pfizer.com/news/articles/sickle_cell_trait_vs_sickle_cell_disease;
[ii] https://www.cdc.gov/ncbddd/sicklecell/facts.html
[iii] https://www.nhlbi.nih.gov/health/sickle-cell-disease
[iv] https://www.rarediseaseadvisor.com/hcp-resource/sickle-cell-disease-life-expectancy/
[v] https://www.cdc.gov/ncbddd/sicklecell/data.html
[vi] https://www.nhlbi.nih.gov/health/sickle-cell-disease/treatment
[vii] https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5045821/
[viii] https://www.changeforscd.com/beyond-vaso-occlusive-episodes-complications/racism-discrimination
[ix] https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3119340/
[x] https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6186193/
[xi] https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4627860/
[xii] https://sickcells.org/wp-content/uploads/2022/08/Sick-Cells_Medicaid-Access-and-Landscape-Review_Final-Report.pdf
[xiii] Ibid.