

Transforming Care for Sickle Cell Disease: A Comprehensive Policy Assessment

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Introduction

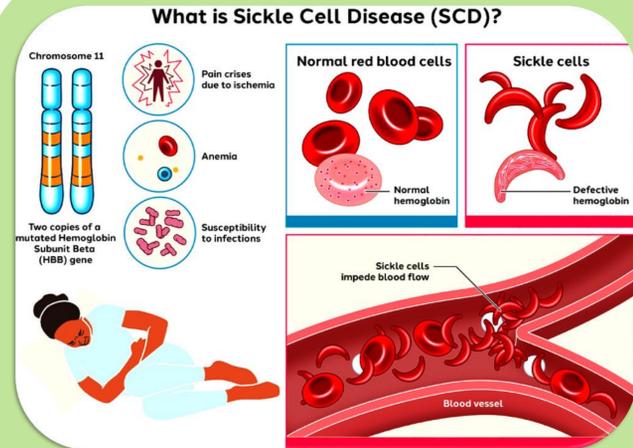


Figure 1: What is Sickle Cell Disease(SCD)? This figure describes SCD, which is a disease of the blood and its effects on patients.

The intersectionality between patients of color and the lack of equitable access to healthcare is due to the social determinants of health and different forms of institutional racism.

Institutional racism is a system of unfair policies and practices that aid in the discrimination or unequal treatment of a minority group and are used to uplift/support another group. Due to the reoccurring, on-going, phenomenon that is institutional racism, systems that were set in place many years ago have a concurrent effect on things happening in today's society, SCD being one. Under hidden layers of brutality and inherent racism lies the medical monstrosity that is SCD and the pain, suffering, and demise of many patients who happen to be people of color.

While there are current laws that have helped patients living with SCD, there are still flaws in this system due to inherent racial biases as well as lack of laws with a more multidisciplinary approach to the matter at hand. SCD requires a multidisciplinary strategy for effective therapy, including pain control, blood-transfusions, medicines, and preventive measures like immunizations and antibiotic prevention. To improve outcomes for those with SCD, regular medical checkups and early intervention for problems are essential. In addition, advocacy, patient education, and support networks are crucial for empowering people and advancing their wellbeing

Background

- Compared to other racial and ethnic groupings, people of African, Mediterranean, Middle Eastern, and Indian heritage have a greater prevalence of Sickle Cell Disease (SCD).
- The "malaria hypothesis" is a phenomena that explains why people of African heritage have a greater frequency of SCD.
- SCD can nonetheless happen to people from other races or ethnic groups if they have the genetic propensity.
- People of African origin have a higher risk of SCD.

Social Determinants of Health



Figure 2: Social Determinants of Health. Describes the SDOH, which are non-medical factors that influence health outcomes. Source: Centers for Disease Control and Prevention

Characteristics of High Frequency & Impact Patients

		Total(N=291)
Demographic Characteristics		Mean +/- SD
Age		27.9 ± 8.1
		% (n)
Sex	Female	58.8 (171)
Race	Black or African American	97.6 (284)
	Other	2.4 (7)
Education	Some high school or less	12.9 (37)
	High school graduate or some college	55.8 (160)
	College graduate or higher	31.4 (90)
Household income	\$25,000 and under	44.2 (102)
	\$25,001 – \$50,000	26 (60)
	\$50,001 – \$75,000	14.7 (34)
	\$75,001 – \$100,000	6.9 (16)
	>\$100,000	8.2 (19)
Employment	Unemployed	34.7 (96)
	Not employed by choice	24.2 (67)
	Working now	41.2 (114)

Table 1. Characteristics of High Frequency and impact Patients. This figure shows the different demographic characteristics of patients that experience high frequencies of pain and impact caused by SCD.

Krisely MR, Tanabe PJ, Yang Q, Masese R, Jiang M, Shah NR. Severe Pain Profiles and Associated Sociodemographic and Clinical Characteristics in Individuals With Sickle Cell Disease. Clin J Pain. 2021 Sep 1;37(9):669-677. doi: 10.1097/AJP.0000000000000957. PMID: 34265788; PMCID: PMC8373671.

Conclusion

In conclusion, tackling racial inequities and health equality in the context of sickle cell disease (SCD) necessitates an all-encompassing strategy. Due to SCD's disproportionate impact on underserved groups, especially those of African origin, legislative adjustments and focused treatments are urgently needed. Prioritizing community participation and involvement in all phases of policy creation and implementation is crucial. Designing effective treatments that cater to the specific needs of those with SCD requires taking into account the opinions and experiences of those people, as well as those of their relatives and community leaders. This strategy ensures that policies are accessible, respectful of different backgrounds, and sensitive to cultural differences.

Addressing the social determinants of health is vital to advancing equal access to health care in SCD. Policies should work to address underlying structural challenges that disproportionately affect communities of color, such as poverty, substandard housing, a lack of educational opportunities, and food insecurity. We can establish environments that promote the best possible well-being and health for people with SCD by putting policies into place that address these socioeconomic factors. Last but not least, continuous analysis of research findings and data is necessary to track advancements, spot gaps, and support evidence-based policy choices. We can provide information that informs policy formulation, clinical practice, and community interventions by encouraging and aiding study efforts that concentrate on SCD and disparities in race.

In order to achieve health equity and reduce racial inequalities in SCD, a comprehensive strategy that incorporates community involvement, healthcare professional training, increased access to care, addressing socioeconomic determinants of health, and supporting research and data gathering is required. We can strive toward a future where people with SCD have equal opportunity for health and well-being, regardless of their racial or ethnic origin, by enacting policies that give priority to these important areas.

Existing Policies

The Louisiana Legislature has passed laws establishing various programs to improve outcomes for individuals living with SCD. Louisiana state law requires the following programs and services be established:

- Louisiana Sickle Cell Commission (LSCC) - The mandate of the Louisiana Sickle Cell Commission (LSCC) is to improve the delivery of sickle cell services to affected people in all parishes of Louisiana.
- SCD Registry – This registry will serve as the statewide repository of accurate and complete records to aid in the cure and treatment of SCD (and other registry protocols and requirements)
- Sickle Cell Patient Navigator Program - This program was intended to increase statewide access to the types of specialty care that are critical to the health and well-being of sickle cell patients
- Sickle cell clinics - Authorizes and directs establishment and operation of clinics for the treatment, holistic care, and counseling SCD.

Recommendations

Recommendation 1: Establishing educational programs for patients and the general public/advertising-

Why?

- It is important to run public awareness initiatives to dispel stereotypes, lessen stigma, and increase understanding of SCD.
- 1a. Establishing educational programs in Louisiana-Louisiana should strive to make their citizens aware of Sickle Cell Disease and its effects on patients living with SCD.
- 1b. Social Media Marketing/Commercials- With social media being the most streamed form of media in today's society, through different commercials and campaigns, SCD should be made aware via numerous social media outlets.
- 1c. Recommended Blood Tests-When receiving a marriage license, Louisiana applicants should be recommended to take a blood test to examine for the Sickle Cell Trait(SCT).

Recommendation 2: Promote Healthy Eating within the SCD Community

Why?

- Many of these patients do not have access to healthy and affordable foods.
- 2a. SNAP Recipients- In an effort to make foods more accessible, SCD patients should be considered to be SNAP recipients.
- 2b. Food Drive/Local Pantries- By having the state partner with big food corporations and stores to create community food stores and or local pantries will begin to solve the economic and health issues in these areas.

Recommendation 3: Updating Louisiana Sickle Cell Commission Policies

Why?

- Some changes should be made to ensure that decisions are being made with equity in mind by people who have the proper training and background regarding equity and race.
- 3a. Equity Training-Prior to appointment, members of the Louisiana Sickle Cell Commission shall undergo equity training as it is a necessary component in learning to eliminate biases in the medical field against SCD patients and ensuring equity for these patients as well.
- 3b. Two Representatives from each race group/community- One representative of the black, latino, and asian caucus appointed by the governor.