

Sickle Cell Disease: Discussing Disparity

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Presenter Disclosures

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The following personal financial relationships with commercial interests relevant to this presentation existed during the past 12 months:

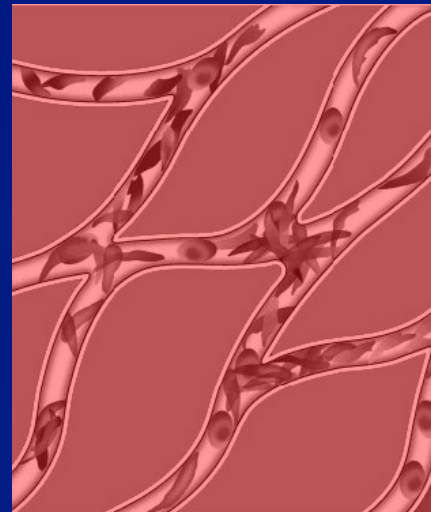
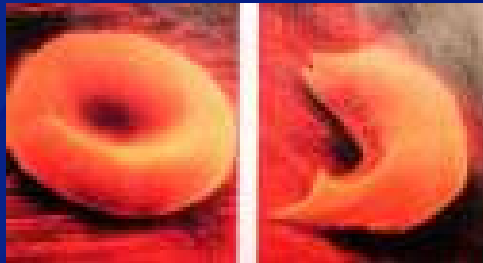
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Health Disparities

- Are differences in "the overall rate of disease incidence, prevalence, morbidity, mortality or survival rates." → race, gender, ethnicity, age, geo-location, disability
- **Sickle Cell Disease (SCD) is both useful and problematic to discuss as a health disparity...**
 - Useful: serves as a prime example how people are differentially invested in and treated
 - Problematic: biological basis for disparity
- **SCD is a biologically based disease that is not race limited yet is associated with differential investment and treatment which likely reveals racism as a root cause for disparity**

What is Sickle Cell Disease (SCD)?

- A genetic blood disorder caused by abnormal hemoglobin that damages and deforms red blood cells
- In a state of low oxygen, sickle hemoglobin (Hemoglobin S) deforms red blood cells causing blockage in the small vessels.



What Do We Know?

Who It Affects

- In the United States, SCD affects approximately
 - 100,000
- Over 3 million Americans have sickle cell trait
 - 1 out of 12 Blacks
 - 1 out of 1400 to 1 out of 36,000 Hispanics
 - 1 out of 58,140 Caucasians

Major Complications

- Anemia, pain, infection, stroke, delayed puberty, delayed growth

Treatment

- Medication, blood transfusions, bone marrow transplant, anti-sickling agents

Public Health Challenges

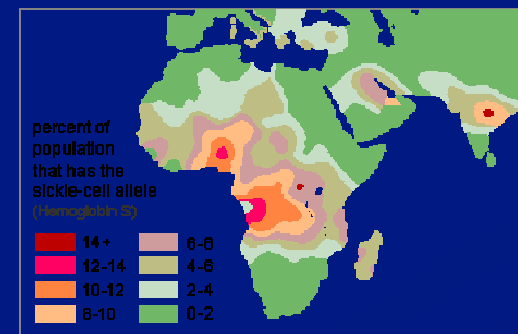
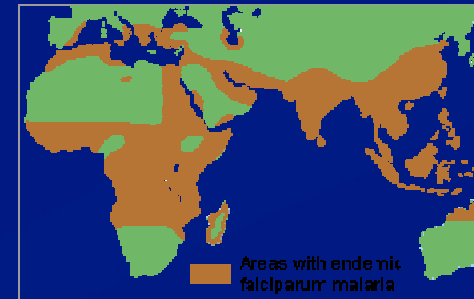
The public health burden, lack of understanding, and lack of resources is significant:

- The total healthcare cost associated with sickle cell disease is 1.1 billion annually¹
- Unknown prevalence in US
- Lack of access to specialty care
- Lack of diffusion of medical knowledge
- Lack of coordination of care & equity in the quality of clinical care
- Lack of community awareness

1. Kauf et al .Am J Hematol. 2009 Jun;84(6):320-2

SCD as a Racialized Disease

- Etiology historically associated with Black race
- Hemoglobin S correlates with the geographic distribution of malaria, not with race
- Notions of Invisibility—
 - Hispanics
 - Northwestern Indians
 - Mediterranean Whites
 - Saudi Arabians



Lundy Braun. "Race, Ethnicity, and Health: can genetics explain disparities," Perspectives in Biology and Medicine. Volume 45(2), Spring 2002, 159-74.

Brief History of Inaction

- 1910—1st report of sickle cell disease in western medicine
- 1920s—medical journals report that SCD was a southern and African American phenomenon
- 1970—Black Panther Party liken the neglect of SCD to genocide
- 1970—JAMA publishes "Health Care Priority and Sickle Cell Anemia"
- 1972—Richard Nixon signs the *Sickle Cell Anemia Control Act* into law

Theoretic Framework: Levels of Racism

Racism: a system of structuring opportunity and assigning value based on the social interpretation of how we look (“race”)

- Unfairly disadvantages some individuals and communities**
- Unfairly advantages other individuals and communities**
- Saps the strength of the whole society through the waste of human resources**

Operates on three levels: institutionalized, personally-mediated, and internalized.

Camara Jones. Confronting Institutionalized Racism. *Phylon* 2003;50(1-2):7-22

Jones CP, Hatch A, Troutman A. Fostering a Social Justice Approach to Health: Health Equity, Human Rights, and an Antiracism Agenda. In RL Braithwaite, SE Taylor, H Treadwell (editors), *Health Issues in the Black Community* (third edition). San Francisco, CA: Jossey-Bass, 2009.

Institutionalized Racism

- **Examples in SCD include:**
 - gainful employment
 - appropriate medical facilities
 - differential access to information
 - resources
 - voice

Personally-mediated Racism

- **Prejudice and discrimination—intentional and unintentional**
- **Manifests itself in SCD as:**
 - Lack of respect—physician's failure to communicate options
 - Suspicion—non belief of pain; belief of drug seeking behavior
 - Devaluation—communication of fatalistic messages
 - Dehumanization –physicians, residents, staff typically deem SCD patients as sub-par; avoidance

Internalized Racism

- **Acceptance by members of the stigmatized races of negative messages about their own abilities and intrinsic worth**
- **Manifests itself in SCD as:**
 - Non communication of disorder to family & friends
 - Belief that one does not deserve good care
 - Fatalistic approach to life
 - Resignation, helplessness, and hopelessness

What is the result?

- **Less than optimal productivity**
- **Higher health-care costs**
- **Social inequity**
- **Other inequities...**

What is inequity?

A system of structuring opportunity and assigning value based on *[fill in the blank: race, social class, geography, nationality, language, legal status, gender, or sexual orientation]* that:

- Unfairly disadvantages some individuals and communities**
- Unfairly advantages other individuals and communities**
- Saps the strength of the whole society through the waste of human resources**

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Sickle Cell Disease: A Question of Equity...

Variable	SCD	Cystic Fibrosis
US prevalence	80,000	30,000
Federal Support (in millions \$)	90	128
CF foundation revenue 2003		152,231,000
SCDAA revenue 2003	498,577	
Total NIH/private support (millions \$)	90.4	280.2
Total support /per person affected with disease \$	1130	9340

Lauren Smith. "Sickle Cell Disease: A Question of Equity and Quality," Pediatrics. Volume 117(5), May 2006, 1763-1770 .

Addressing the Question of Equity

Health Equity → Elimination of Health Disparities

- **How do we achieve health equity?**
 - We value all individuals and populations equally
 - We recognize historical injustices
 - We focus societal efforts to achieve optimal conditions for health for all
- **For SCD:**
 - We stop assigning race to the disease
 - We engage in conversation about ethics and distributive justice

Take Home Points

SCD is a biologically based disease that is not race limited yet associated with differential investment and treatment which likely reveals racism as a root cause for disparity

Acknowledging and confronting racism will be necessary in order to remove the systematic racial biases that affect individuals with SCD

Leading to:

- **Less stigma**
- **Better health outcomes**
- **A more empowered and optimistic patient population**

Acknowledgements

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Thank You!

For more information please contact Centers for Disease Control and Prevention

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The findings and conclusions in this report are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention.

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