The Perspective of African American Teens with Sickle Cell in Massachusetts

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What is Sickle Cell?
Sickle Cell is a group of disorders that causes red blood cells to become misshapen and break down.
If both parents are carriers of the sickle cell gene, they have a 25% chance of any of their children having the sickle cell disease.
Symptoms of Sickle Cell

Fevers

Anemia
When blood produce a lower-than-normal amount of healthy red blood cells

Swollen Hands & Feet
Swelling is caused by sickle-shaped red blood cells blocking blood circulation in the hands and feet.

Vision Problems
Retinal detachment and vision loss from blocked or bleeding blood vessels caused by sickled cells

Frequent infections
Flu, Meningitis, and Pneumonia

Chronic Pain
Pain that lasts most days for 6 months or more.
What is a Health Disparity?

A health disparity is when a certain group of people are more susceptible to a disease or disorder than the rest of the population don't receive the care they deserve because of biases they can't control such as, Race, Gender, Age, Ethnicity, or Religion.
African American teenagers are not likely to receive the help that they need. They fear that they will be turned away or will not be treated well, due to the color of their skin.
Testimony

“A lot of times the ER waits are dangerously long and then even when you do get someone in the ER again, they're not familiar with sickle cell, so they don't how to work with you or then you're blatantly just mistreated because you're thought of as being a drug seeker and this is a disease that we have no control over, that we don't ask for.”

-Massachusetts Sickle Cell Patient
Disparity Data

Figure A

Figure B
Treatment Comparisons

"It gets seven to eleven times the research funding per patient which results in different rates in the development of medicine"
Adolescents with Sickle Cell experience the worse quality of care due to poor communication.

Teens with Sickle cell experience healthcare providers not giving them as strong of medications because of their skin color.
Mistreatment

Video Link
Mistreatments

Two sisters with Sickle Cell were never given the screening test for stroke when diagnosed with sickle cell. This screening could have prevented both of the sisters strokes.

Kyra (Left and Kami (Right)
Raise Your Hand If...
Education & Clubs

- Chronic fatigue or pain can make it appear that students aren't motivated to learn
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- Students with SCD may miss instructions, assignments, and testing.
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- Students with SCD may miss instructions, assignments, and testing
- As well as miss class time or be absent for doctor visits or hospital stays
"Our approach is to **create a true medical home** where patients and their families can **feel seen and heard**. We understand the **complexities of sickle cell disease** and our comprehensive team has the experience to care for you and your family."
Raising Awareness

One organization in Massachusetts helps people struggling with Sickle Cell as well as raise awareness.

They host annual Red Ribbon Galas as well as scholarships awards for people with SCD in Mass
Conclusion

"I just think not only for me but for everyone with sickle cell, things really need to change"

-Massachusetts Sickle Cell Patient


Massachusetts Sickle Cell Association, 2023, sicklecellhope.org/.


Citations (Cont.)


Photos Used


Video

Questions?