DISPARITIES IN SICKLE CELL RESEARCH



WHAT IS SICKLE CELL DISEASE SCD?

AN AUTOSOMAL RECESSIVE DISORDER THAT CAUSES RED BLOOD CELLS TO CHANGE TO A C-SHAPE¹

Complications include anemia, liver problems, organ damage, acute chest syndrome, and more. ²

1 in 365

Sickle cell disease incidence in Black newborns

SICKLE CELL DISEASE IN PREGNANCY

10.91

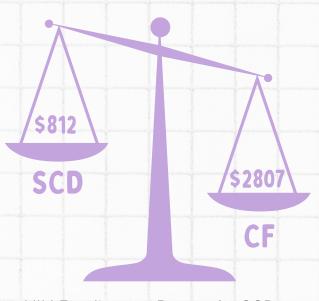
Odds of maternal mortality in pregnant individuals with SCD compared to those without³



Other severe morbidities associated with SCD in pregnancy are bacterial infections, pulmonary thromboembolism, and pulmonary hypertension. Pregnancy complications include preeclampsia, eclampsia, cesarean delivery, abruption, and preterm labor. 5

NEED FOR SCD RESEARCH





NIH Funding per Person for SCD vs cystic fibrosis (CF) ⁶ Lack of federal funding is due in part to the effects of institutional and structural racism that not only affects research but also leads to inadequate healthcare coverage and access to care.

Interpersonal racism can lead to racial disparities in pain management.⁷⁻¹⁰

STRUCTURAL RACISM:

The ways in which perceived societal norms perpetuate racial discrimination in mutually reinforcing systems such as housing, education, employment, earnings, media, healthcare, and criminal justice. 11

INSTITUTIONAL RACISM:

Policies and practices within organizations and institutions that discriminate against certain racial and ethnic minorities.¹²

INTERPERSONAL RACISM:

Words and actions between individuals that exhibit bigotry and biases. 12

PERSONAL RACISM:

Internalized feelings regarding race within individuals.¹²

STRUCTURAL

INSTITUTIONAL

INTERPERSONAL

PERSONAL

INCREASED RESEARCH CAN IMPROVE ACCESS TO HIGH-QUALITY COMPREHENSIVE, AND EVIDENCE-BASED CARE AND INTRODUCES KEY STEPS TO REDUCE RACIAL BIAS AND STIGMA IN HEALTHCARE 6



REFERENCES

- 1. Piel FB, Steinberg MH, Rees DC. Sickle Cell Disease. N Engl J Med. Apr 20 2017;376(16):1561-1573. doi:10.1056/NEJMra1510865
- 2. Centers for Disease Control. Complications of Sickle Cell Disease. Accessed 10/16/2023, https://www.cdc.gov/ncbddd/sicklecell/complications.html
- 3. Boafor TK, Olayemi E, Galadanci N, et al. Pregnancy outcomes in women with sickle-cell disease in low and high income countries: a systematic review and meta-analysis. BJOG: an international journal of obstetrics and gynaecology. Apr 2016;123(5):691-8. doi:10.1111/1471-0528.13786
- Inparaj S, Buckingham M, Oakley L, Seed PT, Lucas S, Oteng-Ntim E. Pulmonary complications for women with sickle cell disease in pregnancy: systematic review and meta-analysis. Thorax. Jul 2020;75(7):568-575. doi:10.1136/thoraxjnl-2019-213796
- 5. Villers MS, Jamison MG, De Castro LM, James AH. Morbidity associated with sickle cell disease in pregnancy. Am J Obstet Gynecol. Aug 2008;199(2):125.e1-5. doi:10.1016/j.ajog.2008.04.016
- 6. Farooq F, Mogayzel PJ, Lanzkron S, Haywood C, Strouse JJ. Comparison of US Federal and Foundation Funding of Research for Sickle Cell Disease and Cystic Fibrosis and Factors Associated With Research Productivity. JAMA Netw Open. Mar 2 2020;3(3):e201737. doi:10.1001/jamanetworkopen.2020.1737
- 7. Evensen CT, Treadwell MJ, Keller S, et al. Quality of care in sickle cell disease: Cross-sectional study and development of a measure for adults reporting on ambulatory and emergency department care. Medicine (Baltimore). Aug 2016;95(35):e4528. doi:10.1097/md.000000000004528
- 8. Kanter J, Smith WR, Desai PC, et al. Building access to care in adult sickle cell disease: defining models of care, essential components, and economic aspects. Blood Adv. Aug 25 2020;4(16):3804-3813. doi:10.1182/bloodadvances.2020001743
- 9. Phillips S, Chen Y, Masese R, et al. Perspectives of individuals with sickle cell disease on barriers to care. PLoS One. 2022;17(3):e0265342. doi:10.1371/journal.pone.0265342
- 10. Hoffman KM, Trawalter S, Axt JR, Oliver MN. Racial bias in pain assessment and treatment recommendations, and false beliefs about biological differences between blacks and whites. Proc Natl Acad Sci U S A. 2016;113(16):4296-4301. doi:10.1073/pnas.1516047113
- 11. American Medical Association. What is structural racism? Accessed October 25, 2023. https://www.ama-assn.org/delivering-care/health-equity/what-structural-racism
- 12. Morgan JD, De Marco AC, LaForett DR, et al. What Racism Looks Like: An Infographic. Frank Porter Graham Child Development Institute. Accessed October 25, 2023. http://fpg.unc.edu/sites/fpg.unc.edu/files/resources/other-resources/What%20Racism%20Looks%20Like.pdf

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