Quantifying the life expectancy gap for people living with sickle cell disease

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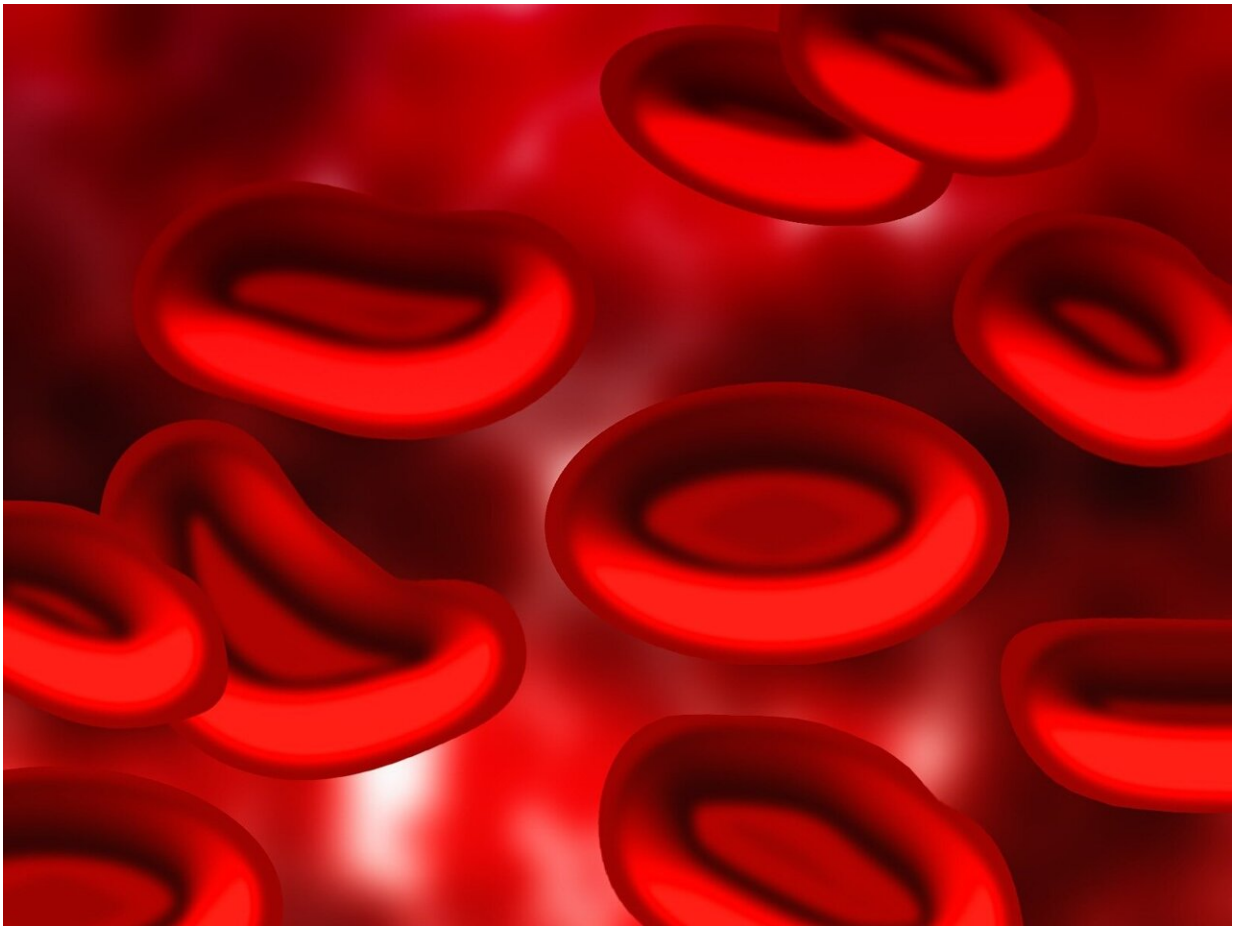

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While research has long established disparities in health outcomes

among individuals living with sickle cell disease (SCD), few studies have quantified these gaps. A new study published in *Blood Advances* finds that the average life expectancy of publicly insured patients living with SCD is roughly 52.6 years. In contrast, the CDC reports that the average life expectancy in the United States is 73.5 years for men and 79.3 years for women, demonstrating the considerable burden SCD can have on affected populations.

Investigators also found that those insured by Medicare for disabilities or end-stage renal disease and those dually insured by Medicare and Medicaid had worse survival outcomes among the populations studied.

SCD is the most common inherited red blood cell disorder in the United States, affecting an estimated 100,000 people. According to the Centers for Disease Control and Prevention (CDC), SCD affects one out of every 365 Black or African American births and one out of every 16,300 Hispanic American births.

"Our study highlights that there is a persistent life expectancy gap among the individuals with sickle cell disease, even though they are covered by public insurance," explained lead study author, Dr. Boshen Jiao, Ph.D., MPH, a researcher in the Comparative Health Outcomes, Policy & Economics (CHOICE) Institute on the Department of Pharmacy at the University of Washington. "The clinical community has known that SCD can be an extremely burdensome condition, however, this study puts numbers behind that burden using real patient data."

Researchers analyzed data from Medicaid Analytic eXtract (MAX) files and Medicare Part A and B Fee-for-Service claims covering enrollees from 2008 to 2016. The data included demographic information, insurance enrollment status, and administrative claims for all individuals with SCD covered by Medicaid or Medicare in all 50 states.

The study included 94,616 individuals with SCD at an average age of 26.6 years across insurance types. Authors reported that 5% of participants had Medicare Old-Age and Survivors Insurance Trust Fund (OASI), 4% had Medicare for disability or end-stage renal disease coverage, 48% had Medicaid, and 43% were dually eligible for Medicare and Medicaid. Of the study population, 74% were Black. Investigators confirmed death dates using death certificates provided by the National Death Index.

Researchers found that the average life expectancy for publicly insured individuals with SCD was 52.6 years, with male life expectancy at birth (49.3 years) being significantly lower than that of females at birth (55 years). However, the study also found that those insured by Medicare for disabilities or end-stage renal disease and those dually insured by Medicare and Medicaid had significantly worse survival outcomes among the populations studied, with an average lifespan of 51.1 years at birth.

Dr. Jiao highlighted that the study demonstrates a persistent life expectancy gap among individuals with SCD, even though they are covered by public insurance. Differences in life expectancies of individuals with SCD across different public insurances most likely reflect the differential burden of comorbidities. However more work is needed to explore these disparities as well as causes of death, which were not available in the National Death Index data linked to CMS claims.

Several care transforming medical interventions for SCD have arisen over the last few decades, such as newborn screening, pneumococcal vaccination, and prophylactic antibiotics, which have dramatically improved the life expectancy of children diagnosed with SCD. Nevertheless, this data illustrates the vast lifespan disparities that persist for those living with SCD.

Dr. Jiao also commented on the high cost of gene therapies for sickle cell disease, a care transforming option on the horizon that is estimated to potentially cost millions of dollars. He emphasized the importance of understanding the long-term effects and value of these therapies to justify their high prices. The study underscores the burden of SCD and its disproportionate impact on Black patients, highlighting the urgent need for a cure.

"While there is no gene therapy for sickle cell disease on the market yet, gene therapies have come out for other diseases, like beta thalassemia, and they cost a lot of money," said Dr. Jiao. "There is substantial optimism that these therapies are valuable to the patients. But because of the high price tag, it becomes even more important that we understand that we are getting enough benefit from these therapies, lifelong, long term, that will justify these high prices."

More information: Boshen Jiao et al, Long-Term Survival with Sickle Cell Disease: A Nationwide Cohort Study of Medicare and Medicaid Beneficiaries, *Blood Advances* (2023). DOI: 10.1182/bloodadvances.2022009202 , dx.doi.org/10.1182/bloodadvances.2022009202

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