Societal Costs of Sickle Cell Disease in the United States

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BACKGROUND
An estimated 100,000 individuals live with sickle cell disease (SCD) in the United States (US), the majority of whom are African American or non-Hispanic American.1–10
SCD is a lifelong and costly inherited disorder caused by hemoglobin polymerization and red blood cell (RBC) sickling, which lead to chronic anemia, hemolysis, and episodic vaso-occlusive crises (VOCS).3–5
The combination of chronic anemia, hemolysis, and vaso-occlusion contributes to a clinical disease course characterized by markedly reduced patient-reported health-related quality of life (HRQOL),3,4 disability, and a lifespan that is reduced by approximately 30 years compared with the general population.6
Available data on the impact of SCD mortality and morbidity on lifetime earnings is limited, which may result in an underestimation of the true premature costs of SCD on patients, their families, and society by relying solely on estimates using direct health care costs.

OBJECTIVE
To estimate the lost lifetime income due to differences in life expectancy among patients with SCD in the US (SCD cohort); an age-, sex-, and race-matched cohort without SCD in the US (non-SCD cohort); and the general US population.

METHODS
To estimate the future impact of SCD on life expectancy and lifetime income, we developed a cohort simulation model using the R statistical program (R Core Team [2017]. R: A language and environment for statistical computing. R Foundation for Statistical Computing, Vienna, Austria. https://www.r-project.org/) (Figure 1).

Table 1. Model Inputs and Sources

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<tr>
<th>Description of Data Input</th>
<th>Population Value (Data Source)</th>
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<td>Estimated incidence rate of newborns with SCD derived from CDC NCHS data (2004-2008)</td>
<td>SCD Cohort</td>
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<td>Number of live births from CDC MCCD file (2020-2021)</td>
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<td>Mortality rates for non-SCD population (black and Hispanic) from CDC-MCCD file</td>
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<td>US Bureau of Census data for race and sex adjustment for SCD age groups</td>
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<td>US Bureau of Census data for US as a whole, and ethnic minority populations</td>
<td>SCD Cohort</td>
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RESULTS

Projected Life Expectancy
The model estimates a birth cohort of 1950 newborns with SCD (SCD cohort; Table 1) compared to just over 1 million in the general US population.

• The projected life expectancy for the SCD cohort was 54 years, which is 22 years less than the life expectancy for the matched non-SCD cohort (76 years) and 25 years less than for the general US population (79 years).

• The estimated quality-adjusted life expectancy for the SCD cohort was 33 years, which was 34 years less than the quality-adjusted life expectancy for the matched non-SCD cohort (67 years) and 36 years less than that for the general US population (69 years).

Projected Lifetime Income

• The projected lifetime income for the SCD cohort was approximately $1,227,389 compared with $1,921,574 for an individual in the matched non-SCD cohort and just over $2 million in the general US population.

• Our estimates represent the current values of future income lost, whereas reduced life expectancy is driven by the need to discount future earnings.

• The difference in lifetime SCD is lost to approximately $700,000 in lifetime income versus an individual without SCD, because of the early mortality associated with SCD.

CONCLUSIONS

• This analysis demonstrated that individuals with SCD experienced more reduced life expectancy, diminished quality of life, the quality-adjusted life expectancy, and significantly lower lifetime earning than individuals without SCD.

• Individuals with SCD were estimated to live 22 years less than a matched cohort of individuals without SCD, and when adjusted for diminished quality of life, the quality-adjusted life expectancy for individuals with SCD was less than half of those without SCD.

• The reduced life expectancy translates into approximately $700,000 in lost lifetime earnings for individuals born with SCD versus those without SCD, equaling to $1.4 billion in lifetime income lost for the 1950 individuals born in the US with SCD, because of premature mortality.

• These losses in lifetime earnings represent only a fraction of the total societal costs because this analysis does not include any direct medical costs or other societal costs (eg, lost educational potential, lost workdays due to caregivers caring for their affected children, or time spent in the hospital or the emergency department), nor does it account for additional challenges in finding and maintaining active employment because of SCD.

• Limitations of this analysis included correcting the CDC MCOD database for underestimating SCD prevalence, using adjacent age groups as a proxy for age groups with undefined death rates, exclusion of fatigue and other important SCD symptoms in utility estimates leading to an overestimation of SCD QALYs, and using current death rates for SCD to estimate future deaths.

• This study shows the substantial societal consequences of SCD beyond the reduction in years required to provide medical care for these patients, underscoring the urgent need to develop disease-modifying therapies that can improve the underlying mortality and lifetime earnings of individuals living with SCD.

REFERENCES


DISCLOSURES

This analysis was sponsored by Global Blood Therapeutics, Inc.

Irene Agodoa: Nothing to disclose.
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