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Blood 142 (2023) 3900–3902

The 65th ASH Annual Meeting Abstracts

POSTER ABSTRACTS

114.SICKLE CELL DISEASE, SICKLE CELL TRAIT AND OTHER HEMOGLOBINOPATHIES, EXCLUDING THALASSEMIAS: CLINICAL AND EPIDEMIOLOGICAL

Estimating Sickle Cell Disease Prevalence By State: A Model Using US-Born and Foreign-Born State-Specific Population Data

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Introduction: Epidemiological data on sickle cell disease (SCD) in the United States is incomplete, particularly at the state level. Current national prevalence estimates do not include SCD cases among people who migrate to the US from high prevalence areas and may result in an underestimation of the size of the prevalent population. To account for this gap, we constructed an epidemiological model that extrapolates SCD prevalent cases based on both US- and foreign-born populations in each state for 2021.
Methods: The total US SCD prevalent cases were estimated by the sum of US- and foreign-born SCD cases for each state. The US-born SCD cases in each state were calculated by applying the prevalence rates derived from new-born-screening studies to the US-born population. The foreign-born SCD cases were calculated by applying the average SCD prevalence rate from the literature for the Caribbean, Western Africa, and Middle and Southern Africa to the corresponding foreign-born populations of each state. These regions were selected due to their high endemic rates of SCD and availability of data required for the extrapolation. Other countries with high prevalence of SCD, such as other African regions, Middle Eastern countries, India, and Brazil, were not included in the analysis due to data limitations. Considering that people with SCD may have a lower propensity to migrate than the general population from these regions, we conservatively assumed that 25% of the total expected population of foreign-born SCD patients in each state would migrate to the US. The migration likelihood adjustment of 25% was based on benchmarking against state-specific SCD prevalence data published by the CDC and other modeling studies. A scenario with no migration adjustment was also explored.
Results: The model estimates that the total number of SCD cases in 50 states and Washington D.C. in the US was 120,156 cases in 2020, with 87% of the cases from the US-born population and 13% of the cases from immigrants from the Caribbean, Western Africa, and Middle and Southern Africa. Florida (13,886 cases), New York (11,715 cases), Texas (9,416 cases), Georgia (7,088 cases), and Maryland (5,812 cases) have the highest SCD burden. In nine states, prevalent SCD cases increased by more than 25% when the non-US-born SCD population is included. The proportion of total SCD cases attributable to immigrants varies widely by state (0-73%). When not adjusting for migration likelihood, the estimate of SCD prevalent cases in the US was 167,484 cases.
Conclusion: The prevalence of SCD and other hemoglobinopathies is growing in the US due to changing migration patterns. The total number of SCD prevalent cases estimated by the model is higher than the frequently cited national estimate of ~100,000 cases. We account for the difference by considering SCD cases from the immigrant population, which was lacking in previous national-level epidemiology estimates that use new-born screening methods. Implications of undercounting SCD cases is significant when considering healthcare resource planning. While the CDC's Sickle Cell Data Collection (SCDC) program is undertaking a significant effort to better understand SCD prevalence at the state level, the scope of the program does not include all US states. More research is needed to obtain accurate and up-to-date SCD epidemiology in the US.
Limitations: This extrapolation is limited by the accuracy of the US-born and foreign-born populations census reporting. US-born SCD prevalent cases may be underestimated as the new-born screening-based SCD prevalence used in the analysis may be outdated. The extrapolation only included the foreign-born population from three regions, which may underestimate SCD prevalent cases. This model does not account for inter-state migration patterns.

Disclosures Fu: *Vertex Pharmaceuticals:* Current Employment, Current holder of *stock options* in a privately-held company. **Andemariam:** *Bluebird:* Consultancy; *GSK:* Consultancy; *Forma Therapeutics:* Consultancy, Research Funding; *Global Blood Therapeutics:* Consultancy, Research Funding; *Emmaus:* Consultancy; *Connecticut Department of Public Health:* Research

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Funding; *Hemanext:* Consultancy, Research Funding; *HRSA:* Research Funding; *Novartis:* Consultancy, Research Funding; *NovoNordisk:* Consultancy; *PCORI:* Research Funding; *Pfizer:* Research Funding; *Sanofi Genzyme:* Consultancy; *Vertex:* Consultancy; *American Society of Hematology:* Research Funding; *Agios:* Consultancy; *Afimmune:* Consultancy; *Accordant:* Consultancy. **Herman:** *Vertex Pharmaceuticals:* Current Employment, Current holder of *stock options* in a privately-held company.

https://doi.org/10.1182/blood-2023-189287

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Table 1. SCD US-Born and Foreign-Born Prevalent Cases by State (Top 5 by Cases)

	US General Population Characteristics		US-born SCD Prevalent Cases	Base Estimate of SCD Prevalent Cases (with 25% Migration Likelihood)			Alternate Scenario Estimate of Prevalent Cases (No Migration Likelihood Adjustment)		
State*	Population in 2020[a]	Foreign-born Population from the Caribbean, Western Africa, Middle and Southern Africa (%)[b]	US-born SCD Prevalent Cases (N)[c]	Base Estimate Foreign-born SCD Prevalent Cases (N)[d]	Total (US-born and Foreign-born) SCD Prevalent Cases (N)[e]	Percentage of Total SCD in Each State Driven by Migration (%)[f]	Foreign-born SCD Prevalent Cases (N)[g]	Total (US-born and Foreign-born) SCD Prevalent Cases (N)[h]	Percentage of Total SCD in Each State Driven by Migration) (%)[i]
All States	331,449,281	1.76%	104,380	15,776	120,156	13%	63,103	167,484	38%
Florida	21,538,187	8.86%	9,930	3,956	13,886	28%	15,825	25,755	61%
New York	20,201,249	6.00%	8,829	2,886	11,715	25%	11,544	20,373	57%
Texas	29,145,505	1.01%	8,241	1,174	9,416	12%	4,697	12,939	36%
Georgia	10,711,908	1.68%	6,506	581	7,088	8%	2,325	8,832	26%
Maryland	6,177,224	2.97%	5,088	724	5,812	12%	2,895	7,983	36%

* States are ordered from largest to smallest based on column e, total (US-born and foreign-born) SCD prevalent cases in base estimate.

a. Population by state obtained from US Census Bureau.
b. Percentage of foreign-born Population from the Caribbean, Western Africa, Middle and Southern Africa in each state were obtained from MigrationPolicy.org.
c. US-born SCD disease estimated by applying state-specific prevalence derived from new-born screening data.
d. Foreign-born SCD Prevalent Cases estimated by applying region-specific SCD prevalence for the Caribbean, Western Africa, Middle and Southern Africa, to the corresponding foreign-born population from these regions in each state. Considering SCD prevalence in the immigrant population may not be the same as prevalence in each country of origin, a 25% migration likelihood adjustment factor was applied to arrive at column d. The 25% factor is determined with benchmarking against state-specific SCD prevalence data published by the CDC and other modeling studies.
e. Total (US-born and foreign-born) SCD prevalent cases is the sum of c and d.
f. The percentage of total SCD in each state driven by migration is calculated as d÷e.
g. Foreign-born SCD Prevalent Cases estimated by applying region-specific SCD prevalence for the Caribbean, Western Africa, Middle and Southern Africa, to the corresponding foreign-born population from these regions in each state, without accounting for migration likelihood.
h. Total adjusted (US-born and foreign-born) SCD prevalent cases is the sum of c and g.
i. Alternate scenario percentage of total SCD in each state driven by migration is calculated as g÷h.

Figure 1