Epidemiology of Sickle Cell Disease in Michigan, 2020

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Background

- Sickle cell disease (SCD) is a lifelong hemoglobinopathy associated with serious health complications, including pain crises and stroke.
- The Michigan Sickle Cell Data Collection (MiSCDC) program is a CDC-funded, population-based surveillance system led by MDHHS and the CHEAR Center at the University of Michigan.
- MiSCDC combines data from multiple sources to understand population trends and healthcare utilization of persons living with SCD in Michigan.

Objective

The objective is to describe the prevalence, demographics, healthcare utilization, and mortality of people living with SCD in Michigan.

Methods

- MiSCDC data were acquired for the most recent complete year available (2020) and were linked and deduplicated on a person-level using Linkage Wiz, a probabilistic data matching tool (Table 1).

Table 1: MiSCDC data sources that were linked and deduplicated (2020)

Data Source	Populations Included
Vital Records	Births and deaths
SCD Clinics	Individuals receiving SCD-related care at clinic
Children's Special Healthcare Services	Children with special healthcare needs covered under Title V funding
Michigan Medicaid	All individuals enrolled in Medicaid
Hospital Discharge	Anyone with emergency department, outpatient, or inpatient encounters in Michigan (all-payer)
Newborn Screening	All infants screened in Michigan since October 1987

- Validated case definitions were used to identify confirmed (newborn screening result or clinical confirmation) and probable (3+ administrative claims for SCD across a 5-year period) cases of SCD living in the state in 2020.
- Demographics were obtained from all data sources and prioritized based on an established data hierarchy.
- Number and length of inpatient admissions, number of emergency department (ED) visits, and county of residence were obtained from administrative claims.
- Mortality in 2020 was assessed using vital records for all individuals with SCD ever living in Michigan.

Results

Figure 1: Inpatient Admission and ED Visit Utilization by Age, 2020
(4,010 persons; 4,271 inpatient admissions; 9,560 ED visits)

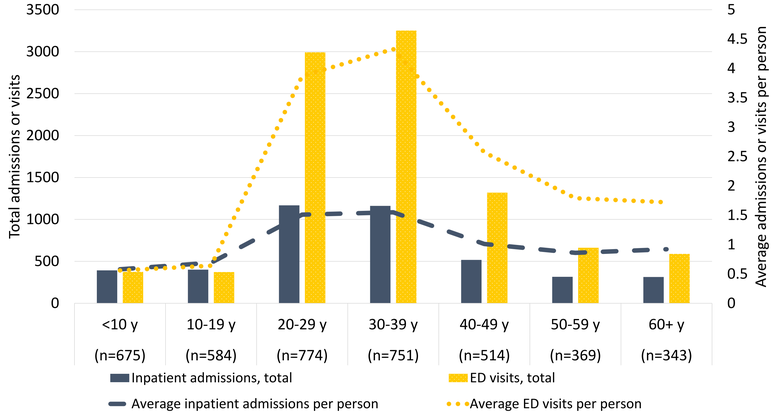
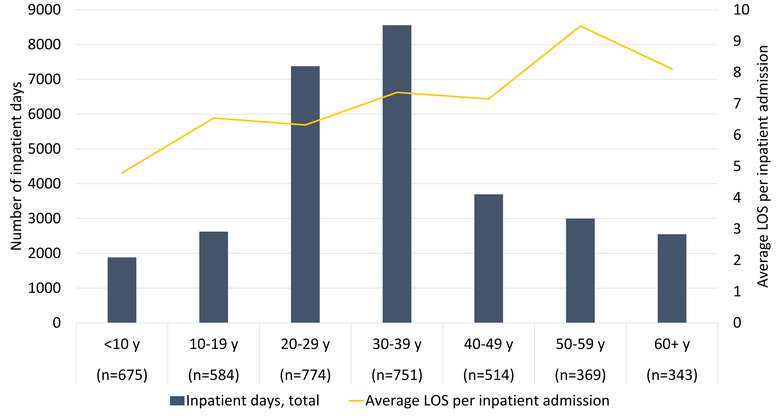


Figure 2: Total Inpatient Days and Average Length of Stay (LOS), 2020
(4,010 persons; 29,675 inpatient days)



Prevalence and Demographics

- We identified 4,010 total persons (58% female) living in Michigan in 2020.
- The average age was 30 years (standard deviation (SD)=19).
- Most persons (63%) resided in southeast Michigan, which includes metro Detroit.

Inpatient Utilization

- In 2020, people with SCD had an average of 1.1 inpatient admissions (SD=3) with an overall average length of stay (LOS) of 7 days (SD=21); Figure 1 details inpatient admissions by age, and Figure 2 details total inpatient days and average LOS by age.
- Inpatient admissions were initiated in the ED 73% of the time and 51% of inpatient admissions occurred within 30 days of another inpatient admission or ED visit.
- Inpatient utilization was reduced in 2020 compared to 2019 (total admissions=4,992 among 3,987 persons; overall mean per person=1.3; overall mean LOS=8.0) for all age groups; although reduced overall, total inpatient days increased for those 30-39 years old in 2020 compared to 2019 (inpatient days=7,922).
- Initiation in ED and 30-day readmissions were similar for both years.

Emergency Department (ED) Utilization

- On average, people with SCD had 2.4 ED visits in 2020 (SD=9); Figure 1 details ED visits by age.
- 68% of ED visits occurred within 30 days of another inpatient admission or ED visit.

Emergency Department (ED) Utilization Ctd.

- ED utilization was reduced in 2020 compared to 2019 (total ED visits=11,396 among 3,987 persons; overall mean per person=2.9) for all age groups except for those 60+ years old.

Mortality

- There were 98 deaths in 2020; the average age at death was 51 years (SD=19).
- The number of deaths in 2020 is approximately 1.5 times greater than 2019, likely due to the COVID-19 pandemic.

Conclusions

- MiSCDC can track trends in the epidemiology and healthcare utilization of people living with SCD in Michigan using linked data sources.
- These findings can be applied to understand the impacts of COVID-19 on this population as well as evaluate disease burden and identify policy targets aimed at improving the quality of life for persons living with SCD.

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