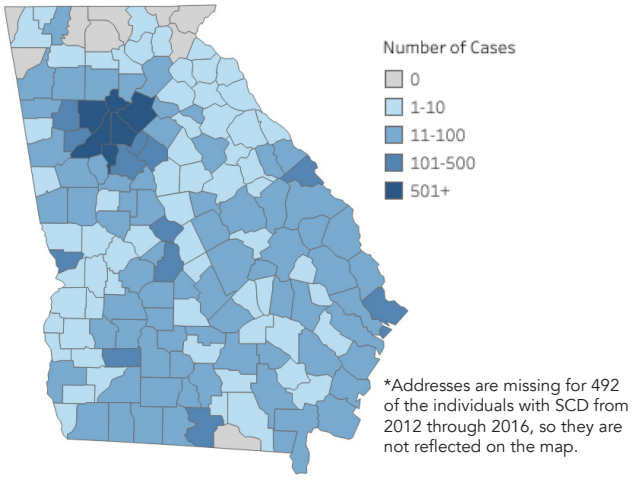
Sickle Cell Data Collection Program Brief: Hospital Encounters Among Adults Living With Sickle Cell Disease in Georgia 2012-2016

August 2020

The Georgia Sickle Cell Data Collection Program (SCDC) identified 5,405 adults[1] living with sickle cell disease in Georgia from 2012 through 2016. Adults with sickle cell disease live in almost every county throughout Georgia.

Nearly nine in 10 (88%) of the identified adults with SCD had at least one hospital or emergency department encounter during the five-year period.

Figure 1: SCD Prevalence in Georgia by County, 2012–2016



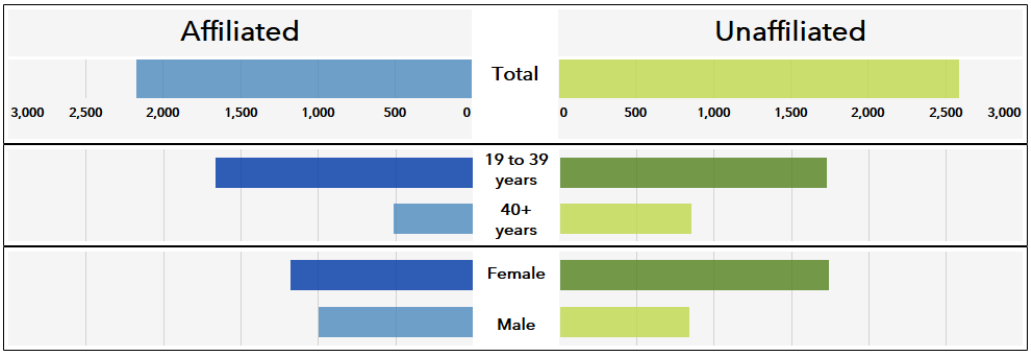
*Addresses are missing for 492 of the individuals with SCD from 2012 through 2016, so they are not reflected on the map.

Affiliated Versus Unaffiliated

Individuals with SCD and at least one hospital or emergency department visit were further categorized as affiliated or unaffiliated with one of Georgia's two adult comprehensive sickle cell treatment centers — Georgia Comprehensive Sickle Cell Center at Grady Memorial Hospital (Atlanta) and the Sickle Cell Center at Augusta University Medical Center.

Affiliated adults were defined as being seen by a comprehensive sickle care treatment center and having a confirmed SCD genotype, while unaffiliated adults met previously established criteria as having a likely SCD diagnosis based on having three or more health care encounters within five years that included an SCD diagnosis, but did not have a visit to a comprehensive sickle cell treatment center. Roughly 46% of adults in this study were affiliated with one of these comprehensive centers.

Figure 2: Demographics of Adults with SCD by Affiliation



Age

Georgia SCDC data confirms that SCD is no longer a "childhood disease" as it once was considered to be, but data show that SCD still impacts life expectancy. For both the affiliated and unaffiliated groups, the majority of adults are aged 19 to 39 versus 40 years and older. However, more older adults tend to be unaffiliated, possibly indicating a more stable disease course and less need for specialty care.

[1]Age is defined as 19 years or older on Jan. 1, 2012.

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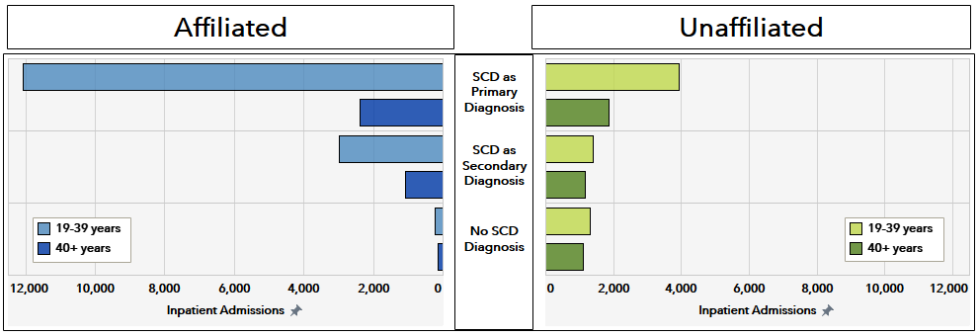
Gender

While the gender breakdown is close to even in the affiliated group, there are nearly two times as many unaffiliated females versus males. Unaffiliated women may be easier to identify through surveillance than men because they are more likely to have Medicaid and use health care services in their early adulthood (reproductive years), and thus are more likely to be captured in administrative data.

Health Care Utilization Is High

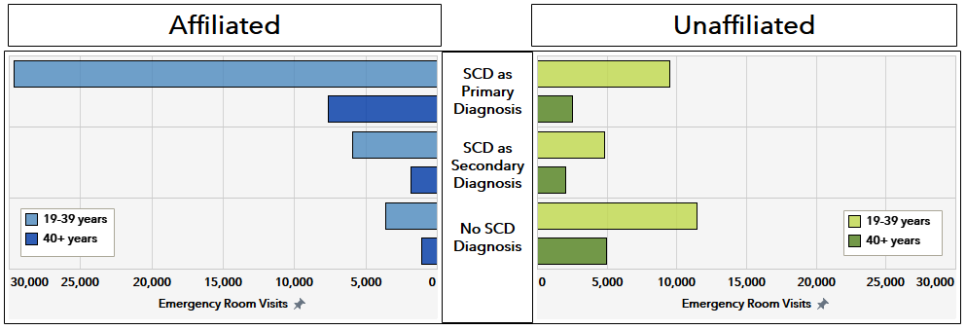
Health care utilization, measured by inpatient admissions and emergency department visits, was higher overall among affiliated adults compared to unaffiliated adults, especially in adults aged 19 to 39 years. This suggests that adults with more severe disease are more likely to be affiliated and receive their care from a comprehensive SCD treatment center. Similarly, affiliated adults 19 to 39 years have a greater share of admissions with SCD as their primary diagnosis, further evidence of SCD complications driving their higher health care utilization.

Figure 3: Inpatient Admissions by Affiliation and SCD Diagnosis



Among affiliated adults, 75% of emergency department visits had a primary diagnosis of SCD. For unaffiliated adults, only 34% of emergency department visits had SCD as primary diagnosis, indicating many unaffiliated adults could have been using the emergency department for non–SCD-related reasons.

Figure 4: Emergency Department Visits by Affiliation and SCD Diagnosis



Furthermore, individuals with SCD over 40 years of age are less likely to have hospital encounters primarily due to SCD. It is possible that older individuals with SCD, particularly the unaffiliated, may have a fairly stable or less severe disease course and are seeking acute care for conditions that surface in middle age in the general population.

Paying for Hospital Encounters

Together, Medicare and Medicaid pay for the majority of all hospital encounters for individuals with SCD for both affiliated and unaffiliated adults in Georgia. Compared to the affiliated, unaffiliated adults disproportionately pay for their emergency department visits themselves (21% versus 9%), which could signal a number of uninsured adults whose main access to health care is the emergency department.

Figure 5: Emergency Department Visits for Individuals with SCD by Payer Type

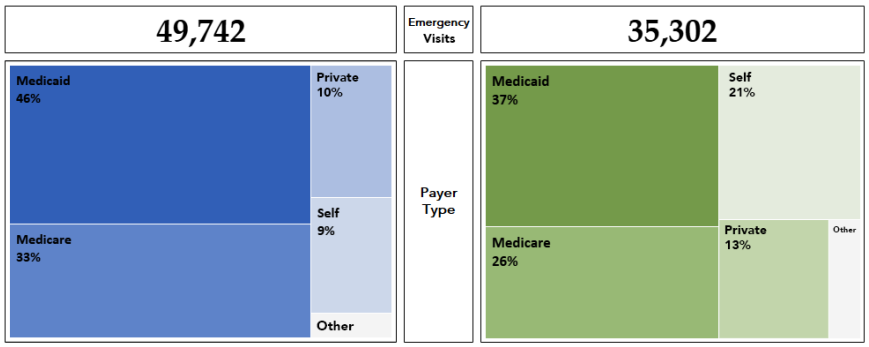
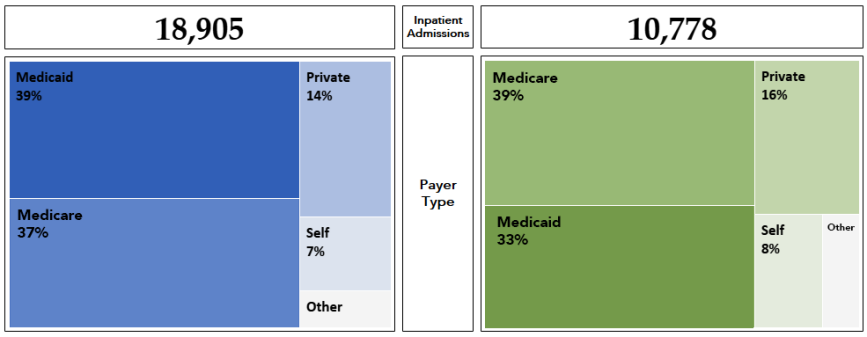


Figure 6: Inpatient Admissions for Individuals with SCD by Payer Type



Limitations

Several limitations of this analysis should be noted. Analysis relied upon administrative data for inpatient and emergency department care and did not include data on outpatient visits. Affiliated individuals received care at a comprehensive sickle cell treatment center at least once, but neither how often nor when they received this care (in relation to their hospital or emergency department use) was considered. Unaffiliated adults may have received outpatient SCD care, but not at a comprehensive sickle cell treatment center.

Remaining Questions

Additional analysis of the timing and frequency of outpatient SCD visits is necessary to study whether adherence to evidence-based preventive treatment and ongoing access to comprehensive SCD care can reduce hospital utilization in SCD patients. Some data suggest that preventing SCD crises may be more difficult than preventing acute exacerbations of other chronic diseases given that individuals with SCD tend to experience clusters of increased health care use around a SCD crisis. Patients are known to have periods when they are really sick and then may have extended periods not needing acute care.

About the Georgia Sickle Cell Data Collection Program

The goal of the Georgia SCDC is to improve the quality of life, life expectancy, and the health of individuals with SCD by developing and disseminating scientific evidence to inform policies and practices. To do this, Georgia SCDC collects health information about people with SCD to study trends in diagnosis, treatment, and health care utilization, in partnership with the U.S. Centers for Disease Control and Prevention.

Connect with SCDC

SCDC nationally: www.cdc.gov/ncbddd/hemoglobinopathies/scdc.html
SCDC Georgia: www.ghpc.gsu.edu/project/hemoglobin-disorders-data-coordinating-center
Contact Angie Snyder (angiesnyder@gsu.edu) if you would like to use SCDC Georgia data for your research or planning.

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