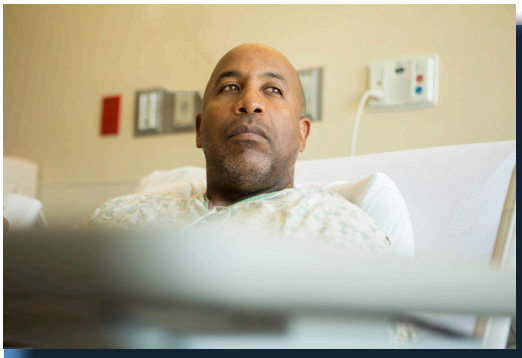

Sickle Cell Data Collection Program Brief: Older Adults Living with Sickle Cell Disease

January 2021

Introduction

Sickle cell disease (SCD) is now usually diagnosed at birth during routine newborn screening, as required in every state. SCD is no longer a "childhood disease" as it once was considered, with the vast majority of those diagnosed now surviving into adulthood and many living well into their 40s, 50s, and beyond. In adulthood, SCD is treated as a chronic condition that often has acute crises and potentially debilitating effects.

Despite interest by patient populations and clinicians, there is very little research or large-scale observation documenting disease course in older adults with SCD. The present analysis uses data from the Sickle Cell Data Collection Program (SCDC) in Georgia and California to describe demographics and survival among older adults with SCD.

Methods

For the current analysis, researchers used longitudinal data from SCDC from both states, applying the previously validated SCDC case definition* to identify adults with SCD who were 45 years old or older at any time from 2004 through 2016. Age was recorded at the time they were first identified in the cohort after their 45th birthday.

Findings

Demographics

Analysis from California SCDC included 1,275 individuals living with SCD who were 45 years old or older. Georgia SCDC identified 915 individuals living with SCD who were 45 years old or older. The vast majority of individuals in both states were 45 to 64 years old versus 65 years or older (California: 96.9% aged 45 to 64 years; Georgia: 91.9% aged 45 to 64 years). Approximately two-thirds of the adults 45 years old or older with SCD in the two states were female (63.6% in California and 66.9% in Georgia).

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* SCDC defines SCD cases as individuals reported by the state newborn screening program with a confirmed diagnosis of SCD, individuals reported by one of the state's hemoglobinopathy specialty treatment centers with a laboratory-confirmed diagnosis of SCD, or individuals with three or more health care visits (hospital, emergency department, or outpatient from more than one provider) with an SCD ICD-9-CM or ICD-10-CM code over any five-year period.

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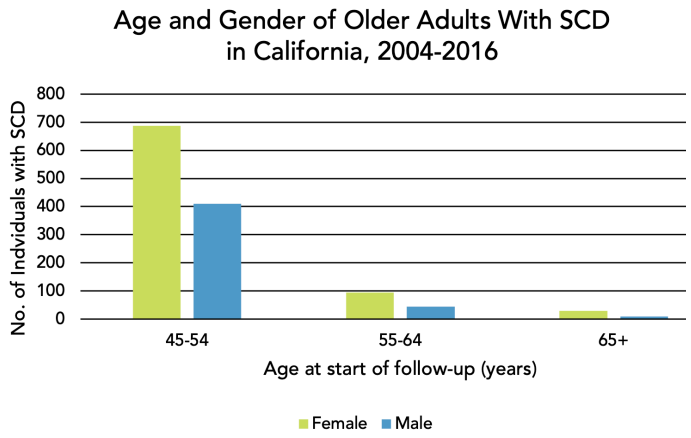
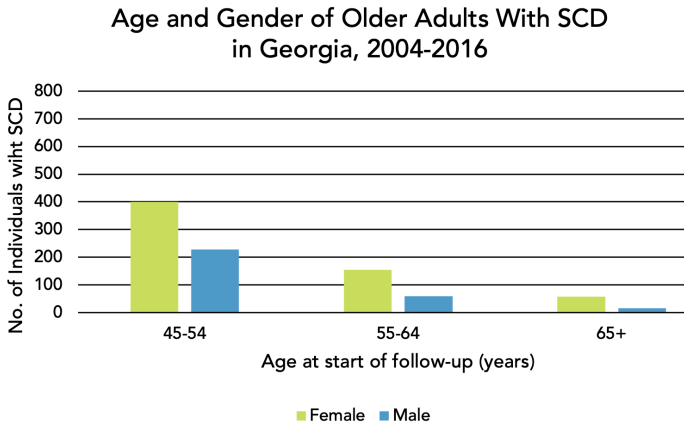
CDC Foundation

SCDC Sickle Cell Data Collection

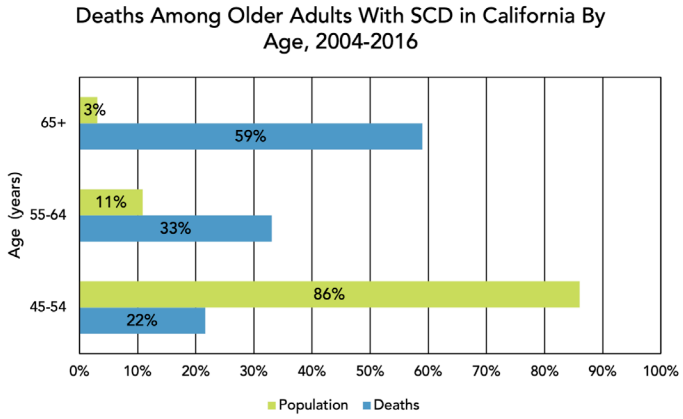
Tracking California
Informing Action for Healthier Communities

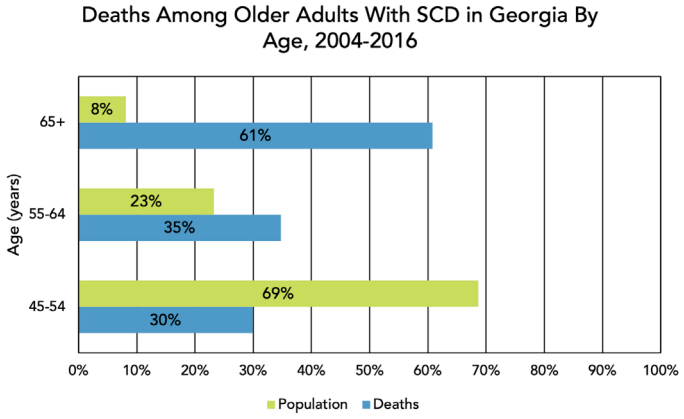




Mortality

In California, overall, 24% of individuals with SCD over the age of 45 years died during the follow-up period (306 of the 1,275). Among adults 45 years old or older with SCD in Georgia, 34% overall died (307 of the 915). Deaths by age group and state are shown below. A similar pattern was seen in both states, with deaths increasing by advancing age group. In California, 22% of those individuals with SCD who were aged 45 to 54 years when entering the study died during the follow-up period, 33% of those aged 55 to 65 years died during follow-up, and 59% died among those 65 or older. In Georgia, for those with SCD entering the study aged 45 to 54 years, 30% died during follow-up, 35% died among those aged 55 to 64 years, and 61% died during follow-up among those 65 or older.





Conclusions

In both California and Georgia, SCDC data confirms that there are many individuals living with SCD who are 45 years old or older. Given the number of individuals with SCD living to an older age, there remains an urgent need for large studies to evaluate evidence-based management of SCD and comorbidities in this population. Further analysis of SCDC data could enable studies of health care utilization patterns, all-cause mortality, and comparisons with similarly aged cohorts in the general population.

About the Sickle Cell Data Collection Program

The goal of 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, SCDC collects health information about people with SCD to study trends in diagnosis, treatment, and health care utilization.

Connect with SCDC

SCDC nationally: www.cdc.gov/ncbddd/hemoglobinopathies/scdc.html
SCDC Georgia: www.ghpc.gsu.edu/project/hemoglobin-disorders-data-coordinating-center
SCDC California: https://casicklecell.org/cadata/
Contact Angie Snyder (angiesnyder@gsu.edu) if you would like to use SCDC Georgia data for your research or planning, Susan Paulukonis (Susan.Paulukonis@cdph.ca.gov) to use SCDC California data, or Mary Hulihan (mhulihan@cdc.gov) regarding multistate data.