Emergency Department Visits by Individuals with Sickle Cell Disease in Texas, 2023

TEXAS Health and Human Services
Texas Department of State Health Services

TEXAS SCDC
Sickle Cell Data Collection

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Acknowledgments

The Texas Sickle Cell Data Collection Program (Texas SCDC) thanks all national, state, and community partners for their dedication, hard work, and collaboration. Their efforts help implement a state sickle cell data collection system and play a significant role in supporting the sickle cell disease community in Texas.

About the Texas Sickle Cell Data Collection Program

In 2023, the Texas Department of State Health Services (DSHS) received funding from the Centers for Disease Control and Prevention (CDC) to establish Texas SCDC, a state sickle cell data collection system that informs sickle cell disease practices and policies in Texas. Texas SCDC is one of 16 states funded by the CDC. The goal of Texas SCDC is to collect, maintain, and disseminate high quality sickle cell data that will contribute to improving diagnoses, treatments, survival, and quality of life for all individuals with sickle cell disease in Texas. Texas SCDC provides information on all individuals with sickle cell disease in Texas, regardless of age, insurance status, or geography.

Texas SCDC Funding

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Suggested Citation

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Report Overview

Background

Sickle cell disease (SCD) is one of the most prevalent and clinically significant blood disorders in the United States. It is estimated that by 2050, the number of people living with sickle cell disease will grow by 30 percent.[1]

SCD is characterized by an abnormal hemoglobin protein, causing misshapen red blood cells that appear crescent- or sickle-shaped. Non-sickle hemoglobin carries oxygen to organs, muscles, and the brain to support normal body processes. Sickle hemoglobin break down rapidly and are unable to flow normally through the blood vessels, causing a range of serious health concerns that include chronic pain, acute pain crises, acute chest syndrome, stroke, organ damage, increased risk of severe infections, and reduced longevity. The unpredictable nature and severity of acute crises result in frequent utilization of emergency care among individuals with sickle cell disease.

Purpose

The purpose of this report is to examine emergency department visits by individuals with sickle cell disease in 2023 using deidentified data from the DSHS Texas Health Care Information Collection (THCIC) to better understand emergency health care seeking patterns and outcomes related to sickle cell disease.

About the Data

This report utilizes data from the THCIC Hospital Emergency Department Public Use Data Files. THCIC's charge is to collect and report data on health care activity in hospitals and health maintenance organizations operating in Texas. All emergency medical care facilities and departments in operation in Texas are required to report all patient emergency medical care visits and related claims.

THCIC Texas Hospital Emergency Department Public Use Data Files include data from the THCIC Hospital Inpatient Public Use Data Files and the THCIC Hospital Outpatient Public Use Data Files. In this report, Texas SCDC examined only emergency department data from the THCIC Texas Hospital Outpatient Public Use Data Files. The outpatient component of the THCIC Texas Hospital Emergency Department Public Use Data Files contain deidentified patient-level information for emergency department visits that did not go more than twenty-four (24) hours from the time patients are treated in the hospital or freestanding emergency medical care facility. Within this report, these emergency department visits will be referred to as "ED visits".

Texas SCDC analyzed a subset of the THCIC Hospital Emergency Department Public Use Data Files based on SCDC International Classification of Disease, Tenth Revision, Clinical Modification Codes (ICD-10-CM codes) (Appendix A, Table 5). As the THCIC Hospital Emergency Department Public Use Data Files are aggregate in nature, results of this analysis should be interpreted as individual encounters and not as individual patient data (i.e., the same individual may appear multiple times throughout the data set if they were treated or hospitalized more than once in Texas in 2023).

Report Summary

Sickle Cell Disease Emergency Care

- In 2023, a total of 19,109 ED visits by individuals with SCD were reported to the THCIC system.
- The highest rates of ED visits by individuals with SCD in 2023 were in Health Service Region 4 (122 visits per 100,000 individuals) and Health Service Region 5 (145 visits per 100,000 individuals).

Demographics of Sickle Cell Disease Emergency Care

- Black, Non-Hispanic (92.9 percent) was the most common race/ethnicity among ED visits by individuals with SCD in 2023 followed by Hispanic (3.7 percent) and Other, Non-Hispanic (2.1 percent).
- Of the examined age groups, the highest number of ED visits by individuals with SCD in 2023 was by 30- to 39-year-olds (31.6 percent) followed by 20- to 29-year-olds (24.5 percent).
- Children and youth (birth to 24 years old) accounted for 6,065 (31.7 percent) of ED visits by individuals with SCD in 2023.

Reasons and Outcomes for Sickle Cell Disease Emergency Care

- *Hemoglobin SS disease with crisis unspecified* (51.2 percent) was the most common principal diagnosis code among ED visits by individuals with SCD in 2023, followed by *Sickle-cell disease without crisis* (8.3 percent) and *Sickle-cell/Hemoglobin C disease unspecified* (1.9 percent).
- Most individuals with SCD who visited the ED in 2023 were discharged to home or self-care (91.2 percent), whereas others left against medical advice (5.5 percent) or were discharged to other short term general hospital (1.9 percent).
- In 2023, 10 ED visits by individuals with SCD resulted in death.

Emergency Care Costs

- In 2023, the total costs of ED visits by individuals with SCD in Texas was $175,100,328 and the average cost per ED visit was $9,163.
- The highest cost for an ED visit by an individual with SCD in 2023 was $216,146.

Sickle Cell Disease Emergency Care

In 2023, a total of 19,109 ED visits by individuals with SCD were reported to the THCIC system (Appendix B, Table 6).

The highest rates of ED visits by individuals with SCD in 2023 were in Health Service Region 4 (122 visits per 100,000 individuals) and Health Service Region 5 (145 visits per 100,000 individuals) (Figure 1). Additional County-Level data is available in Appendix C, Figure 5.

Sickle cell anemia (Hemoglobin SS Disease) was the most common type of SCD recorded across all diagnosis code fields of ED visits by individuals with SCD in 2023 (Appendix A, Table 5; Appendix B, Table 6).

Hb-SS disease with crisis unspecified (51.2 percent) was the most common principal diagnosis among ED visits by individuals with SCD in 2023, followed by *Sickle-cell disease without crisis* (8.3 percent) and *Sickle-cell/Hb-C disease unspecified* (1.9 percent) (Table 1).

Additional information regarding SCD genotypes is available in Appendix C, Table 7.

Figure 1: Emergency Department Visit Rates by Patient Residence Health Service Region, Texas, 2023

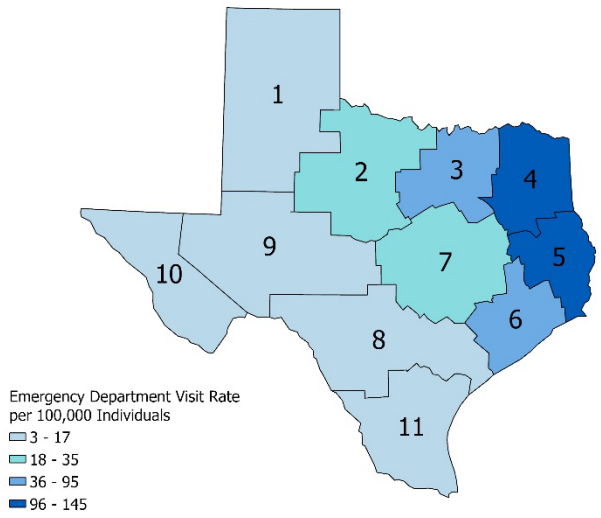


Table 1: Principal Diagnoses of Emergency Department Visits by Individuals with Sickle Cell Disease, Texas, 2023

ICD-10-CM Codes and Definition		Emergency Department Visits	
		Number	Percent
D57.00	*Hb-SS disease with crisis unspecified*	9,787	51.2%
D57.1	*Sickle-cell disease without crisis*	1,587	8.3%
D57.219	*Sickle-cell/Hb-C disease unspecified*	370	1.9%
R07.9	*Chest pain, unspecified*	286	1.5%
D57.819	*Other sickle-cell disorders unspecified*	263	1.4%
R07.89	*Other chest pain*	232	1.2%
R50.9	*Fever, unspecified*	211	1.1%
U07.1	*COVID-19*	182	1.0%
M54.5	*Low back pain, unspecified*	167	0.9%
J06.9	*Acute Upper Respiratory Infection*	144	0.8%

Demographics of SCD Emergency Care

There are an estimated 100,000 Americans with SCD in the United States, of which 7,000 are estimated to be Texans.[2] Other state SCD data collection systems have determined the prevalence of SCD within their state to be higher than previously estimated.[3]

In Texas, total ED visits by individuals with SCD in 2023 was similar across patient sex – 8,899 female (47.0 percent) and 9,434 male (49.4 percent) patients (Appendix B, Table 6).

Black, Non-Hispanic (92.9 percent) was the most common ethnicity/race among emergency department visits by individuals with SCD followed by Hispanic (3.7 percent), and Other, Non-Hispanic (2.1 percent) (Table 2; Appendix B, Table 6).

Of the examined age groups, the highest number of ED visits by individuals with SCD was by 30- to 39-year-olds (31.6 percent) followed by 20- to 29-year-olds (24.5 percent) (Figure 2).

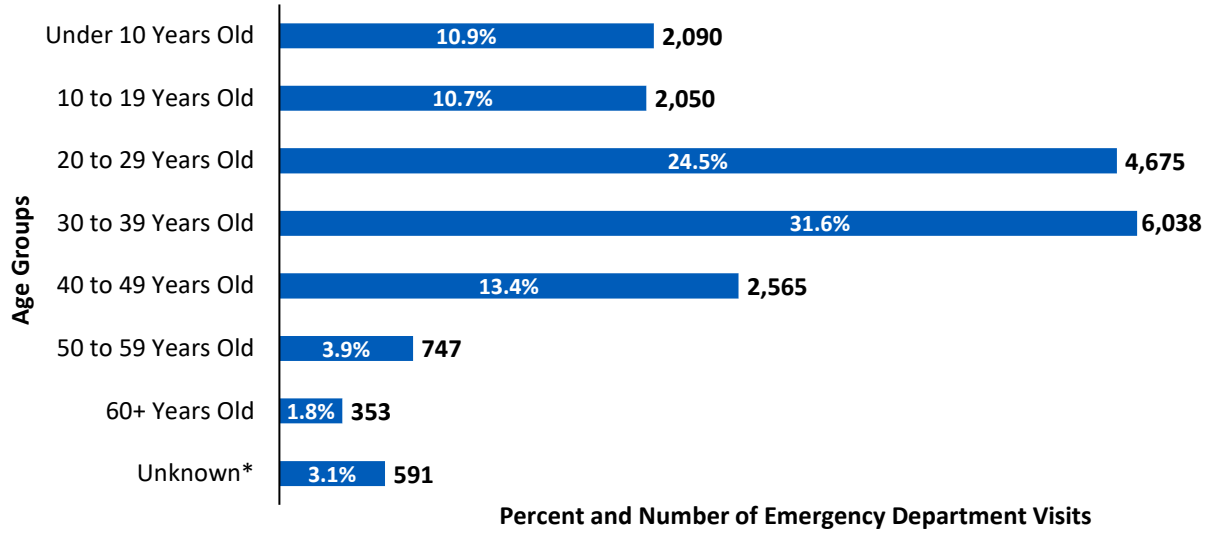
Additional demographic information is available in Appendix B, Table 6 of this report.

Table 2: Emergency Department Visits by Individuals with Sickle Cell Disease by Race/Ethnicity, Texas, 2023

Race/Ethnicity	Emergency Department Visits	
	Number	Percent[1]
Hispanic	706	3.7%
Black, Non-Hispanic	17,758	92.9%
White, Non-Hispanic	196	1.0%
Asian or Pacific Islander, Non-Hispanic	30	0.2%
American Native, Non-Hispanic	15	0.1%
Other, Non-Hispanic	401	2.1%
Unknown[2]	3	0.02%
Total	19,109	100%

1. Proportions may not equal to 100 due to rounding.
2. Missing ethnicity/race information for sickle cell disease encounters.

Figure 2: Emergency Department Visits by Individuals with Sickle Cell Disease by Age Group, Texas, 2023



*Includes patient visits with missing information or containing ICD-10-CM codes indicating drug or alcohol use and/or HIV/STD Diagnosis.

Children and Youth SCD Emergency Care

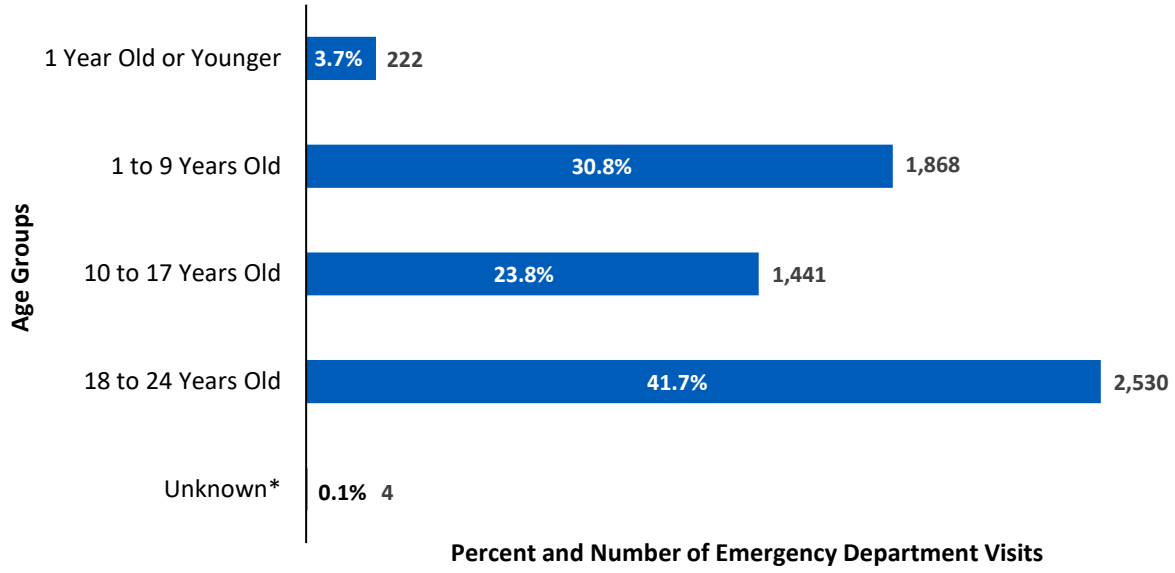
Any period of hospitalization may adversely impact pediatric physical and psychosocial development.[4,5] Children with SCD face a heightened risk of long-term anemia, major pain crisis, splenic sequestration, stroke, and other serious health concerns that may impact their school attendance and performance, socialization, and achievement of key childhood milestones.[5,6]

The transition from pediatric to adult healthcare typically occurs between the ages of 18 and 22 years, however, each case is unique with some transitions to adult healthcare occurring earlier or later.[7] This age group often coincides with major life changes that may lead to difficulty managing health and wellbeing, especially for youth living with SCD.

In 2023, children and youth accounted for 6,065 (31.7 percent) of the 19,109 total ED visits by individuals with SCD (Appendix D, Table 8). Those 18 to 24 years old accounted for 41.7 percent of ED visits by children and youth with SCD (Figure 3; Appendix D, Table 8). There were similar trends of patient sex among children and youth with SCD (48.2 percent female and 51.4 percent male) compared to ED visits by individuals with SCD across all ages (Appendix D, Table 8). Black, Non-Hispanic (90.7 percent) was the most common ethnicity/race among ED visits by children and youth with SCD, followed by Hispanic (5.9 percent) and Other, Non-Hispanic White (1.8 percent) (Appendix D, Table 8).

Among all children and youth with SCD, the most common principal diagnosis was *Hemoglobin SS disease with crisis unspecified* (41.3 percent), followed by *Sickle-cell disease without crisis* (9.5 percent) and *Fever, unspecified* (3.4 percent) (Appendix D, Table 8).

Figure 3: Emergency Department Visits by Children and Youth with Sickle Cell Disease by Age Group, Texas, 2023



*Includes patient visits with missing information or containing ICD-10-CM codes indicating drug or alcohol use and/or HIV/STD Diagnosis.

SCD Emergency Care Outcomes

For individuals with SCD, the ED may be the only option when symptoms cannot be managed at home or when SCD-informed healthcare providers are unavailable.[8,9] Individuals with SCD may seek emergency care an average of three times each year between 18 to 60 years of age.[8]

Most individuals with SCD in Texas who visited the ED in 2023 were discharged to home or self-care (91.2 percent), whereas others left against medical advice (5.5 percent) or were discharged to other short term general hospital (1.9 percent) (Table 3).

In 2023, 10 ED visits by individuals with SCD in Texas resulted in death (Table 3).

*Table 3: Top 10 Discharges of Emergency Department Visits by Individuals with Sickle Cell Disease, Texas, 2023**

Discharge Outcome	Emergency Department Visits	
	Number	Percent
Discharged to home or self-care (routine discharge)	17,420	91.2%
Left against medical advice	1,053	5.5%
Discharged to other short term general hospital	371	1.9%
Discharge/transfer to another type of health care institution not defined elsewhere in the code list	48	0.3%
Discharged/transferred to court/law enforcement	48	0.3%
Discharged/transferred to a designated cancer center or children's hospital	48	0.3%
Discharged/transferred to psychiatric hospital or psychiatric distinct part of a hospital	23	0.12%
Discharged to care of home health service	18	0.09%
Admitted as inpatient to this hospital	13	0.07%
Deceased	10	0.05%

*Only the top 10 of 42 discharge outcomes are provided in this table. The provided counts in this table will not add up to the total 19,109 emergency department visits referenced throughout this report.

SCD Emergency Care Insurance and Costs

Individuals with SCD often have considerable unmet healthcare needs and face substantial financial healthcare costs. It has been estimated that lifetime healthcare costs for an individual with SCD could be as high as $8,747,908 assuming a 50-year life expectancy and not accounting for inflation.[9]

In 2023, the total cost of ED visits by individuals with SCD in Texas was $175,100,328 (Appendix E, Table 9).

Most ED visits by individuals with SCD in 2023 cost between $1,000 and $9,999 per visit (Figure 4), with the average cost being $9,163 (Appendix E, Table 9).

The highest cost for an ED visit by an individual with SCD in Texas in 2023 was $216,146 (Appendix E, Table 9).

Most ED visits by individuals with SCD in Texas in 2023 were covered by Medicaid (46.8 percent) (Figure 5).

Figure 4: Range of Costs for Emergency Department Visits by Individuals with Sickle Cell Disease, Texas, 2023

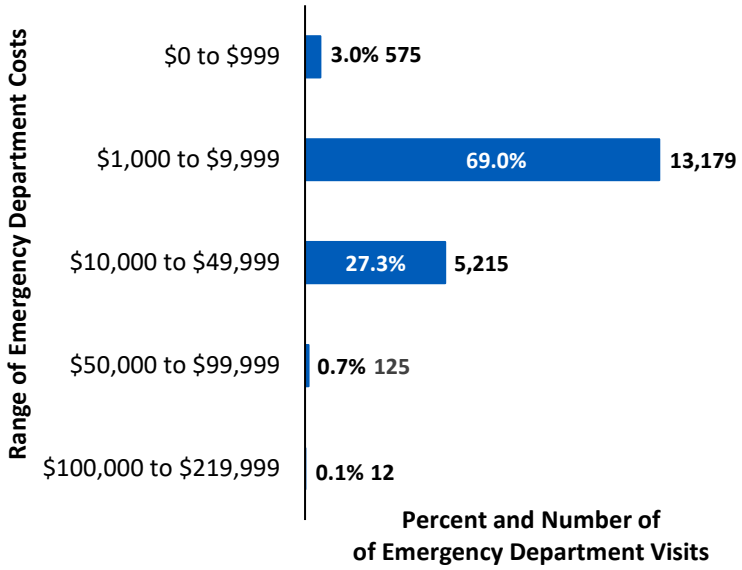
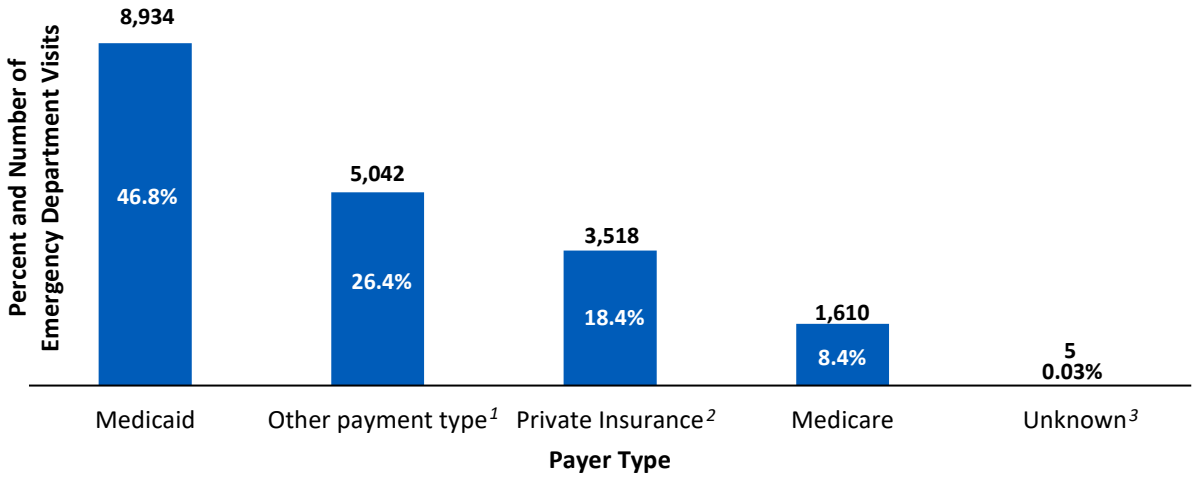


Figure 5: Payer Type Among Emergency Department Visits by Individuals with Sickle Cell Disease, Texas, 2023



1. Other payment types include Self-Pay, Central Certification, Other Non-Federal Programs, Point of Service, Indemnity Insurance, Automobile Medical, Commercial Insurance, Disability Insurance, Liability Medical, Workers Compensation Claim, Other Federal Program, Veteran Administration Plan, Civil Health and Medical Program of the Uniformed Services, Title V, Charity, Indigent
2. Private Insurance includes Preferred Provider Organization, Exclusive Provider Organization, Blue Cross/Blue Shield, Health Maintenance Organization
3. Missing payer type information for sickle cell disease visits

Reasons for SCD Emergency Care

SCD is a chronic condition associated with complications and comorbidities, including acute pain crises.[10,11] Individuals with SCD face unique challenges accessing healthcare, including the unavailability of SCD-informed healthcare providers, skepticism when reporting levels of pain, and stigmatization as drug seekers.[10,11,12] Preventing ED visits by individuals with SCD involves proactive care and management as informed by healthcare providers who specialize in SCD.

In 2023, the most common reason individuals with SCD in Texas sought emergency care was *Hemoglobin SS disease with crisis unspecified* (29.3 percent), followed by *Chest pain, unspecified* (6.2 percent), and *Dorsalgia, unspecified* (Back Pain) (5.9 percent) (Table 4).

A 2019 survey identified challenges among healthcare providers in understanding the needs of patients with SCD, highlighting a demand for additional support for healthcare providers serving patients with SCD.[13]

*Table 4: Top 10 Patient Reasons for Emergency Department Visits by Individuals with Sickle Cell Disease, Texas, 2023**

ICD-10-CM Code and Definition		Emergency Department Visits	
		Number	Percent
D57.00	*Hb-SS disease with crisis unspecified*	5,596	29.3%
R07.9	*Chest pain, unspecified*	1,189	6.2%
M54.9	*Dorsalgia, unspecified (Back Pain)*	1,131	5.9%
R50.9	*Fever, unspecified*	1,000	5.2%
M54.50	*Low back pain, unspecified*	737	3.9%
D57.1	*Sickle-cell disease without crisis*	621	3.3%
R52	*Pain, unspecified*	524	2.7%
R10.9	*Unspecified abdominal pain*	508	2.7%
M79.10	*Myalgia, unspecified site (Muscle Pain)*	373	2.0%
R05.9	*Cough, unspecified*	311	1.6%

*Only the top 10 of over 700 patient reasons for emergency department visit outcomes are provided in this table. The provided counts in this table will not add up to the total of 19,109 emergency department visits referenced throughout this report.

Data Sources and References

Data Sources

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Appendix A: SCD ICD-10-CM Codes

Table 5. Sickle Cell Disease ICD-10CM Codes by SCD Genotype and Billing Status, 2023

ICD-10-CM Code		SCD Genotype	Billable/Unbillable*
D57.0	HB-SS disease with crisis	Hemoglobin SS disease	Unbillable
D57.00	Hb-SS disease with crisis unspecified	Hemoglobin SS disease	Billable
D57.01	Hb-SS disease with acute chest syndrome	Hemoglobin SS disease	Billable
D57.02	Hb-SS disease with splenic sequestration	Hemoglobin SS disease	Billable
D57.03	Hb-SS disease with cerebral vascular involvement	Hemoglobin SS disease	Billable
D57.04	Hb-SS disease with dactylitis	Hemoglobin SS disease	Billable
D57.09	Hb-SS disease with crisis with other specified complication	Hemoglobin SS disease	Billable
D57.2	Sickle-cell/Hb-C disease	Hemoglobin SC disease	Unbillable
D57.20	Sickle-cell/Hb-C disease without crisis	Hemoglobin SC disease	Billable
D57.21	Sickle-cell/Hb-C disease with crisis	Hemoglobin SC disease	Unbillable
D57.211	Sickle-cell/Hb-C disease with acute chest syndrome	Hemoglobin SC disease	Billable
D57.212	Sickle-cell/Hb-C disease with splenic sequestration	Hemoglobin SC disease	Billable
D57.213	Sickle-cell/Hb-C disease with cerebral vascular involvement	Hemoglobin SC disease	Billable
D57.214	Sickle-cell/Hb-C disease with dactylitis	Hemoglobin SC disease	Billable
D57.218	Sickle-cell/Hb-C disease with other specified complication	Hemoglobin SC disease	Billable
D57.219	Sickle-cell/Hb-C disease unspecified	Hemoglobin SC disease	Billable
D57.413	Sickle-cell/Hb-C disease with cerebral vascular involvement	Hemoglobin SC disease	Billable
D57.42	Sickle-cell thalassemia beta zero without crisis	Hemoglobin S/Beta 0 thalassemia	Billable
D57.43	Sickle-cell thalassemia beta zero with crisis	Hemoglobin S/Beta 0 thalassemia	Unbillable
D57.431	Sickle-cell thalassemia beta zero with acute chest syndrome	Hemoglobin S/Beta 0 thalassemia	Billable
D57.432	Sickle-cell thalassemia beta zero with splenic sequestration	Hemoglobin S/Beta 0 thalassemia	Billable
D57.433	Sickle-cell thalassemia beta zero with cerebral vascular involvement	Hemoglobin S/Beta 0 thalassemia	Billable
D57.434	Sickle-cell thalassemia beta zero with dactylitis	Hemoglobin S/Beta 0 thalassemia	Billable
D57.44	Sickle-cell thalassemia beta plus without crisis	Hemoglobin S/Beta + thalassemia	Billable
D57.45	Sickle-cell thalassemia beta plus with crisis	Hemoglobin S/Beta + thalassemia	Unbillable
D57.451	Sickle-cell thalassemia beta plus with acute chest syndrome	Hemoglobin S/Beta + thalassemia	Billable
D57.452	Sickle-cell thalassemia beta plus with splenic sequestration	Hemoglobin S/Beta + thalassemia	Billable
D57.453	Sickle-cell thalassemia beta plus with cerebral vascular involvement	Hemoglobin S/Beta + thalassemia	Billable
D57.454	Sickle-cell thalassemia beta plus with cerebral vascular involvement	Hemoglobin S/Beta + thalassemia	Billable
D57	Sickle-cell disorders	Other Sickle Cell Disease	Billable
D57.1	Sickle-cell disease without crisis	Other Sickle Cell Disease	Billable
D57.4	Sickle-cell thalassemia	Other Sickle Cell Disease	Unbillable
D57.40	Sickle-cell thalassemia without crisis	Other Sickle Cell Disease	Billable
D57.41	Sickle-cell thalassemia, unspecified, with crisis	Other Sickle Cell Disease	Unbillable
D57.411	Sickle-cell thalassemia, unspecified, with acute chest syndrome	Other Sickle Cell Disease	Billable
D57.412	Sickle-cell thalassemia, unspecified, with splenic sequestration	Other Sickle Cell Disease	Billable
D57.414	Sickle-cell thalassemia, unspecified, with dactylitis	Other Sickle Cell Disease	Billable
D57.418	Sickle-cell thalassemia, unspecified, with other specified complication	Other Sickle Cell Disease	Billable
D57.419	Sickle-cell thalassemia, unspecified, with crisis	Other Sickle Cell Disease	Billable
D57.438	Sickle-cell thalassemia with other specified complication	Other Sickle Cell Disease	Billable
D57.439	Sickle-cell thalassemia unspecified	Other Sickle Cell Disease	Billable
D57.458	Sickle-cell thalassemia with other specified complication	Other Sickle Cell Disease	Billable
D57.459	Sickle-cell thalassemia unspecified	Other Sickle Cell Disease	Billable
D57.8	Other sickle-cell disorders	Other Sickle Cell Disease	Unbillable
D57.80	Other sickle-cell disorders without crisis	Other Sickle Cell Disease	Billable
D57.81	Other sickle-cell disorders with crisis	Other Sickle Cell Disease	Unbillable
D57.811	Other sickle-cell disorders with acute chest syndrome	Other Sickle Cell Disease	Billable
D57.812	Other sickle-cell disorders with splenic sequestration	Other Sickle Cell Disease	Billable
D57.813	Other sickle-cell disorders with cerebral vascular involvement	Other Sickle Cell Disease	Billable
D57.814	Other sickle-cell disorders with dactylitis	Other Sickle Cell Disease	Billable
D57.818	Other sickle-cell disorders with crisis with other specified complication	Other Sickle Cell Disease	Billable
D57.819	Other sickle-cell disorders unspecified	Other Sickle Cell Disease	Billable

*Billable/Unbillable references which ICD-10-CM codes are covered by insurance. Both sets of codes may be used by a physician and each type of codes was included to capture every encounter involving an individual with sickle cell disease.

Appendix B: Demographic Data

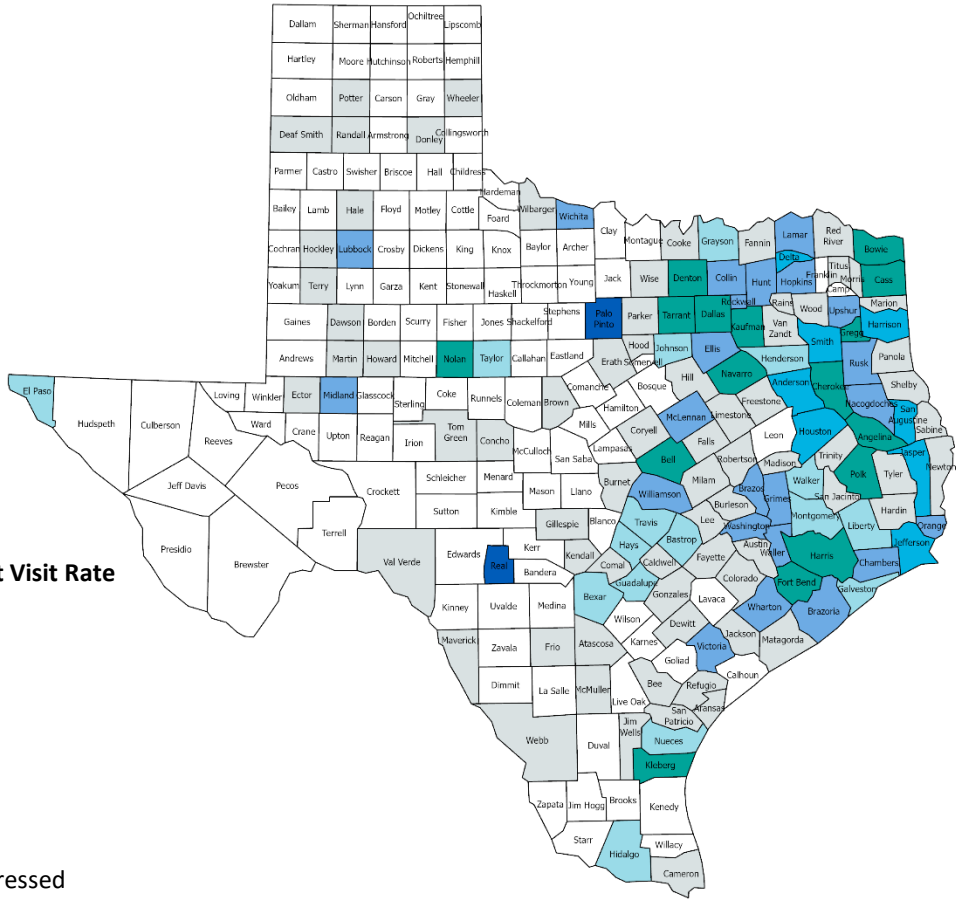
Table 6. Characteristics of Emergency Department Visits by Individuals with Sickle Cell Disease, Texas, 2023

	Emergency Department Visits	
	Number	Percent[1]
Total	19,109	100%
Sex		
Female	8,988	47.0%
Male	9,434	49.4%
Unknown	687	3.6%
Age group		
Under 10 Years Old	2,090	10.9%
10 to 19 Years Old	2,050	10.7%
20 to 29 Years Old	4,675	24.5%
30 to 39 Years Old	6,038	31.6%
40 to 49 Years Old	2,565	13.4%
50 to 59 Years Old	747	3.9%
60+ Years Old	353	1.9%
Unknown[2]	591	3.1%
Race/Ethnicity		
Hispanic	706	3.7%
Black, Non-Hispanic	17,758	92.9%
White, Non-Hispanic	196	1.0%
Asian or Pacific Islander, Non-Hispanic	30	0.2%
American Native, Non-Hispanic	15	0.1%
Other, Non-Hispanic	401	2.1%
Unknown[3]	3	0.02%
Sickle Cell Disease Genotype		
HbSS (Sickle Cell Anemia)	11,608	60.8%
HbSC (SC Disease)	853	4.5%
HbS beta^{+} Thalassemia	41	0.2%
HbS beta^{0} Thalassemia	29	0.2%
Other SCD Disorders	6,578	34.4%
Patient State[4]		
Texas	18,745	98.1%
Bordering State (AR, LA, NM, OK)	109	0.6%
All Other U.S States	252	1.3%
Foreign Country	3	.02%

1. Proportions may not equal to 100 due to rounding.
2. Includes patient visits with missing information or containing ICD-10-CM codes indicating drug or alcohol use and/or HIV/STD Diagnosis.
3. Missing ethnicity/race information for sickle cell disease encounters.
4. Patient state derived from patient mailing address listed on health care claim (complete mailing address is unavailable in the public use data files).

Appendix C: SCD ED Visit County Map

Figure 5. Map of Emergency Department Visit Rates per 100,000 by County of Residence, Texas, 2023 [1,2]



Emergency Department Visit Rate per 100,000 Individuals

- 0
- 1 -27
- 28 - 81
- 82 - 177
- 178 - 378
- 379 – 1,014
- Rate Data Suppressed

1. The results of this analysis were calculated from aggregate data and should be interpreted as individual encounters and not as individual patient data (i.e., the same individual may appear multiple times throughout the data set if they were treated or hospitalized more than once in Texas in 2023).
2. Rates for counties with 1 to 15 emergency department visits were suppressed due to reliability issues. Suppression of Rates and Counts | U.S. Cancer Statistics | CDC

Appendix D: Sickle Cell Disease Genotypes

Table 7. Sickle Cell Disease Genotype Information

Sickle Cell Disease Genotype	Information
Hemoglobin SS or HbSS	HbSS is the most common type of sickle cell disease (SCD). A person with HbSS inherits two genes, one from each parent, that code for hemoglobin "S." Hemoglobin S is an abnormal form of hemoglobin that causes the red blood cells to become rigid and sickle shaped. This is commonly called sickle cell anemia and is usually the most severe form of the disease.
Hemoglobin SC or HbSC	A person with HbSC inherits a hemoglobin S gene from one parent and a gene for a different type of abnormal hemoglobin called "C" from the other parent. This is usually a milder form of SCD.
HbS beta^{+} thalassemia	A person with HbS beta^{+} thalassemia inherits a hemoglobin S gene from one parent and a gene for beta thalassemia, another type of hemoglobin abnormality, from the other parent. A person with HbS beta^{+} thalassemia produces varying amounts of hemoglobin A. HbS beta^{+} thalassemia is a milder form of SCD.
HbS beta^{0} thalassemia	A person with HbS beta^{0} thalassemia inherits a hemoglobin S gene from one parent and a gene for beta thalassemia, another type of hemoglobin abnormality, from the other parent. A person with HbS beta^{0} thalassemia does not produce hemoglobin A. HbS beta^{0} thalassemia is a more severe form of SCD.
Other SCD Disorders	Hemoglobin SD (HbSD), hemoglobin SE (HbSE), and hemoglobin SO (HbSO) are other types of sickle cell disease. A person with one of these forms of SCD inherits one hemoglobin S gene and one gene that codes for another abnormal type of hemoglobin ("D," "E," or "O"). These are very rare forms of SCD with varying severity.

Appendix E: Demographic Data of Children and Youth with SCD

Table 8. Characteristics of Emergency Department Visits by Children and Youth with Sickle Cell Disease, Texas, 2023

	Emergency Department Visits	
	Number	**Percent[1]**
Total	6,065	100%
Sex		
Female	2,922	48.2%
Male	3,115	51.4%
Unknown	28	0.47%
Age group		
1 Year Old or Younger	222	3.7%
1 to 9 Years Old	1,868	30.8%
10 to 17 Years Old	1,441	23.8%
18 to 24 Years Old	2,530	41.7%
Unknown[2]	4	0.1%
Race/Ethnicity		
Hispanic	360	5.9%
Black, Non-Hispanic	5,500	90.7%
White, Non-Hispanic	72	1.2%
Asian or Pacific Islander, Non-Hispanic	16	0.3%
American Native, Non-Hispanic	10	0.2%
Other, Non-Hispanic	106	1.8%
Unknown[3]	1	0.02%
Top Five Common Principal Diagnosis		
D57.00-*HB-SS Disease with Crisis Unspecified*	2,502	41.3%
D57.1-*Sickle-Cell Disease without Crisis*	575	9.5%
R50.9-*Fever, Unspecified*	205	3.4%
D57.219-*Sickle-Cell/HB-C Disease Unspecified*	117	1.9%
U07.1-*Covid-19*	102	1.7%

1. Proportions may not equal to 100 due to rounding.
2. Includes patient visits with missing information or containing ICD-10-CM codes indicating drug or alcohol use and/or HIV/STD Diagnosis.
3. Missing ethnicity/race information for sickle cell disease encounters.

Appendix F: Cost of SCD Emergency Care

Table 9. Cost of Emergency Department Visits by Individuals with Sickle Cell Disease (n=19,109), Texas, 2023

	Cost of Emergency Department Visits Dollar Amount
Minimum	$0
Maximum	$216,146
Mean	$9,163
Median	$6,894
Total Sum	**$175,100,328**

Appendix G: Data Limitations

The following limitations are associated with the THCIC Hospital Emergency Department Public Use Data Files[a].

- Up to 25 diagnosis codes, up to 25 procedure codes, and up to 10 external cause of injury codes can be submitted. Sicker patients may not be accurately represented in the data. This may also result in total volume and percentage calculations for diagnoses and procedures not being complete.
- Sex is suppressed for patients with an ICD-10 code that indicates drug use, alcohol use, or an HIV-STD diagnosis. Suppression of this data element is applied separately within inpatient and outpatient data sets [Title 42, United States Code, section 290dd-2(g) and Title 42 of the Code of Federal Regulations Part 2: Confidentiality of Substance Use Disorder Patient Records (Part 2)].
- The last two digits of the ZIP code are suppressed if there are fewer than thirty patients included in the ZIP code. The entire ZIP code is suppressed for patients with an ICD-10 code that indicates drug use, alcohol use, an HIV-STD diagnosis, or if a hospital, or a Freestanding Emergency Medical Care Facility (FEMCF) has fewer than five discharges of a particular gender, including 'unknown' [Title 42, United States Code, section 290dd-2(g) and Title 42 of the Code of Federal Regulations Part 2: Confidentiality of Substance Use Disorder Patient Records (Part 2)].
- Patient race and ethnicity data are required by law and rule to be submitted for each patient. Generally, these data are not collected by facilities directly from the patient and may be subjectively captured and reported by the facilities [Texas Health and Safety Code, Section 108.009(k)].
- Race is changed to 'Other' and ethnicity is suppressed if a hospital, an ambulatory surgical center (ASC), or an FEMCF has fewer than ten discharges of a particular race [Texas Health and Safety Code, Sections 108.013(c)(1) 108.013 (g)].
- The data are a snapshot in time. Hospitals and FEMCFs must submit data no later than 60 days after the close of a calendar quarter. Depending on hospital and FEMCFs' collection and billing cycles, not all inpatient discharge encounters from ED visits or outpatient ED visits may have been billed or reported during the particular quarter the patient received the services. Those services may appear in the following quarter's data. This can affect the accuracy of source of payment data, particularly self-pay and charity that may later qualify for Medicaid, Medicare, or other payment sources.
- DSHS collects data from all hospitals, and FEMCFs in the state not specifically exempted (and not owned by the United States of America). Some hospitals may be exempted from reporting for certain situations (for example, natural or other disasters, or other unusual conditions) for limited time periods.
- The healthcare facility patient mix (the types of patients treated at healthcare facilities vary, due to the healthcare facility's interest and specialty services availability) should be considered when drawing conclusions about the data or making comparisons with other data.
- Any conclusions drawn from the data are subject to errors caused by the inability of the facility to communicate complete data due to form constraints, subjectivity in the assignment of codes, system mapping, and clerical error. The data are submitted to DSHS providers as their best effort to meet statutory requirements.

For more information regarding THCIC and their data limitation, visit Texas Emergency Department Public Use Data File | Texas DSHS or refer to their data dictionary at EDPUDFDataDictionary4Q2023.pdf.

TEXAS
Health and Human Services

Texas Department of State Health Services

TEXAS
SCDC
Sickle Cell Data Collection

https://www.dshs.texas.gov/environmental-epidemiology-disease-registries-section-eedrs/Sickle-Cell-Data-Collection