

Sickle Cell Patients Are Living a Decade Longer in 2022 Than in 2008

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Key Findings

- The median age at death for patients diagnosed with sickle cell disease has increased 20%, from 50 years in 2008 to 60 years in 2022.
- In 2022, 50.0% of patients diagnosed with sickle cell disease were 60 years old or older when they died, compared to 38.9% in 2016.

Sickle cell disease (SCD) is an inherited condition in which there is a mutation in the patient's red blood cells. Patients often develop acute and severe pain episodes, chronic hemolytic anemia, and organ damage.¹ Treatment often targets pain management and prevention or mitigation of vaso-occlusive episodes or organ damage including cardiopulmonary disease, kidney disease, and central nervous system disease.¹ Over the past decade, the FDA approved three new medications for the treatment of SCD: L-glutamine, crizanlizumab, and voxelotor.¹⁻⁴ We sought to understand how the median age at death for patients with SCD has changed over time.

We studied 5,954 patients with SCD and 5,171,437 patients without SCD who died between 2008 and 2022 to determine the median age at death for each population. We found that the median age at death for patients with SCD increased 20%, from 50 years of age in 2008 to 60 years of age in 2022. The median age at death for patients without SCD stayed consistent, with a median of 75 years in both 2008 and 2022.

Median Age at Death for Patients with and Without Sickle Cell Disease

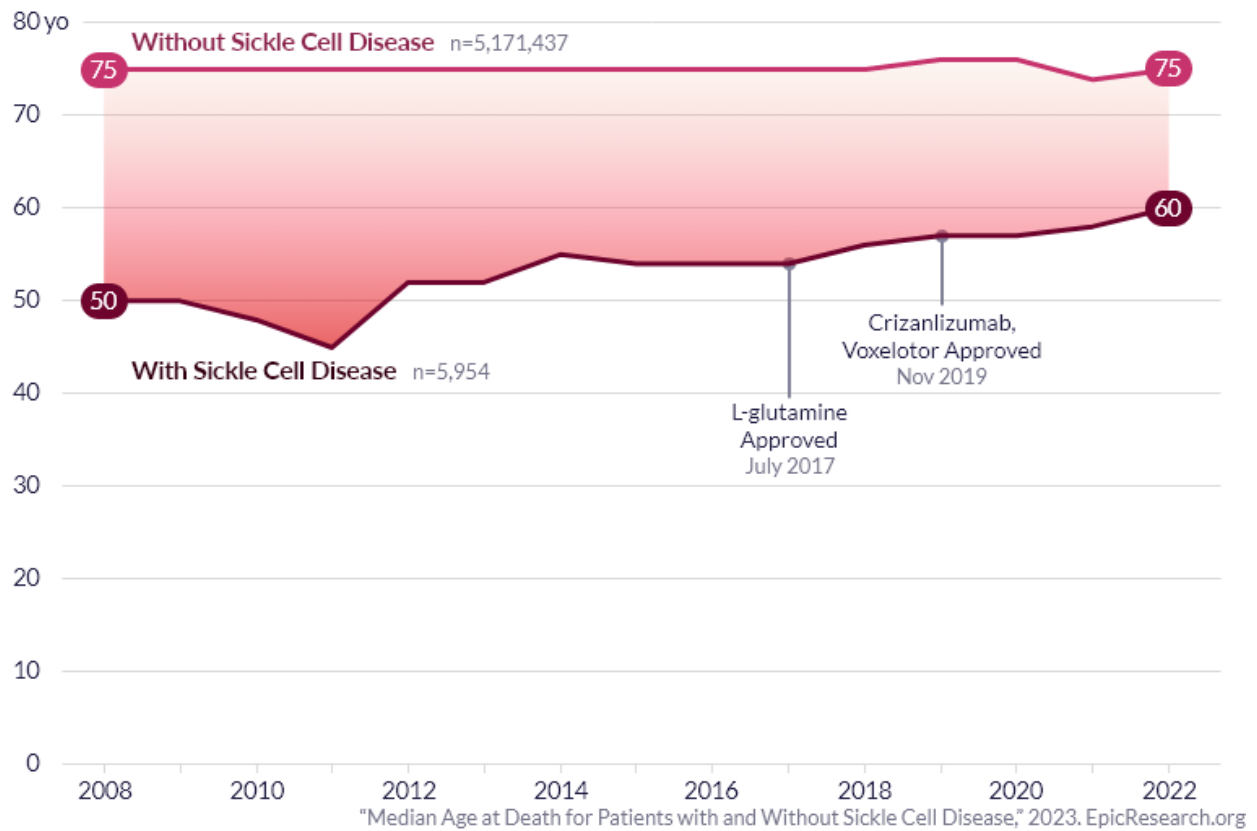
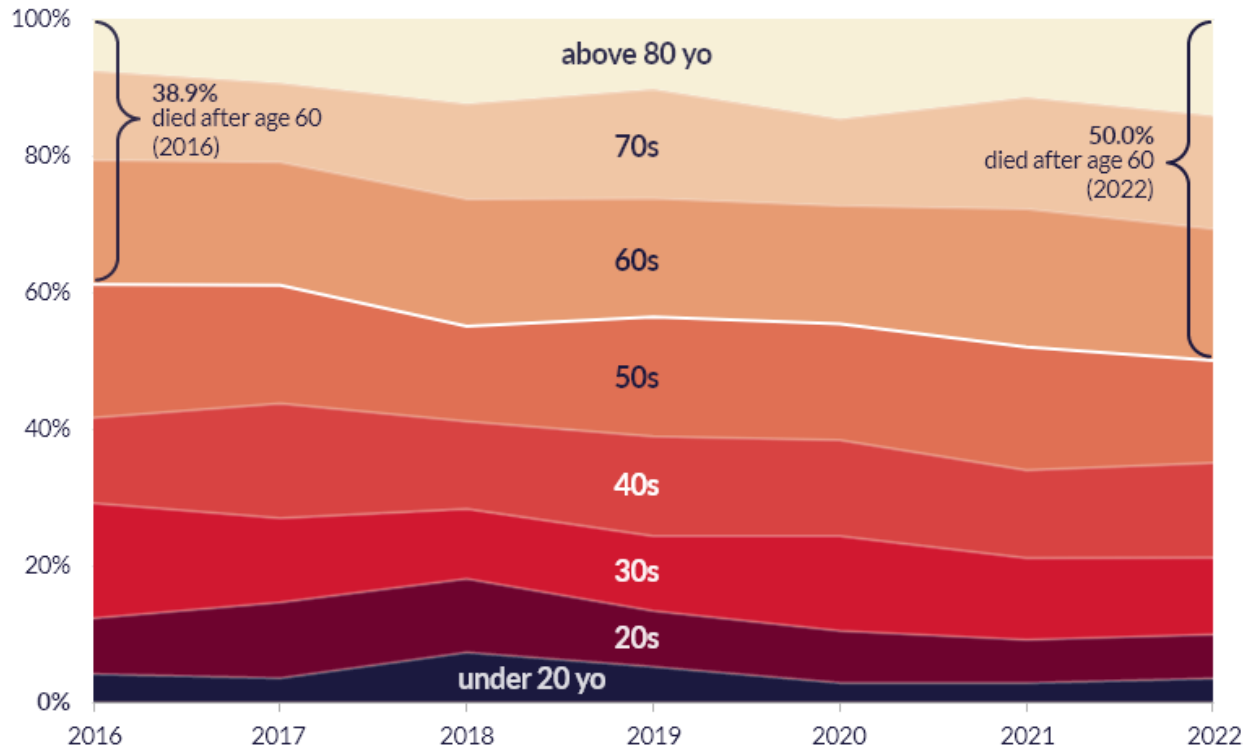


Figure 1. Median age at death for patients who died each year with and without sickle cell disease from 2008 to 2022.

We further stratified the age at death for patients with SCD each year to understand how the proportions of deaths in each decade of life have changed over time. In 2016, 38.9% of patients with SCD who died were older than 60. In 2022, that proportion increased to 50.0% of patients diagnosed with SCD who died after age 60.

Proportion of Annual Deaths by Age for Patients with Sickle Cell Disease



n=4,578

"Proportion of Annual Deaths by Age for Patients with Sickle Cell Disease," 2023. EpicResearch.org

Figure 2. Proportion of deaths for patients with sickle cell disease in each age group by year of death from 2016 to 2022.

These data come from Cosmos, a HIPAA-defined Limited Data Set of more than 214 million patients from 218 Epic organizations including 1,235 hospitals and more than 26,800 clinics, serving patients in all 50 states and Lebanon. This study was completed by two teams that worked independently, each composed of a clinician and research scientists. The two teams came to similar conclusions. Graphics by Brian Olson.

References

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2. Center for Drug Evaluation, & Research. (2019, February 9). FDA approved L-glutamine powder for the treatment of sickle cell disease. U.S. Food and Drug Administration; FDA. <https://www.fda.gov/drugs/resources-information-approved-drugs/fda-approved-l-glutamine-powder-treatment-sickle-cell-disease>
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4. Center for Drug Evaluation, & Research. (2019c, December 20). FDA approves voxelotor for sickle cell disease. U.S. Food and Drug Administration; FDA. <https://www.fda.gov/drugs/resources-information-approved-drugs/fda-approves-voxelotor-sickle-cell-disease>

Data Definitions

Term	Definition
Study period	2008-2022 (year of death)
Study population	Sickle cell disease identified by one of the following ICD-CM-10 codes: D57.* excluding D57.3 Death date populated
Exposures	Year of death
Outcomes	Age of death

Table 1: Median Age at Death for Patients with and Without Sickle Cell Disease

Year	With Sickle Cell Disease		Without Sickle Cell Disease	
	Median Age at Death	Count	Median Age at Death	Count
2008	50	18	75	54,175
2009	50	313	75	71,754
2010	48	28	75	95,597
2011	45	70	75	136,733
2012	52	140	75	185,411
2013	52	202	75	231,653
2014	55	234	75	270,844
2015	54	310	75	309,155
2016	54	368	75	344,815
2017	54	405	75	410,682
2018	56	512	75	470,514
2019	57	591	76	526,854
2020	57	820	76	648,589
2021	58	983	74	707,462
2022	60	960	75	707,199

Table 2: Proportion of Annual Deaths by Age for Patients with Sickle Cell Disease

Sickle Cell Disease Proportion of Annual Deaths by Age Group							
Age	2016	2017	2018	2019	2020	2021	2022
Under 20	15	14	35	29	23	27	33
20s	30	45	52	46	62	62	62
30s	62	50	49	62	114	117	108
40s	46	68	62	82	115	126	133
50s	72	70	67	99	140	177	144
60s	67	73	90	98	142	198	185
70s	48	47	67	90	104	160	159
Above 80	28	38	60	58	120	112	136