

Spina Bifida Patients Are Living 15 Years Longer in 2022 Than in 2011

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Key Findings:

- The median age at death for patients diagnosed with spina bifida increased by 36.6% (from 41 to 56 years old) from 2011 to 2022.
- In 2022, 70.8% of patients diagnosed with spina bifida were 40 years old or older when they died, compared to 52.0% in 2014.

Spina bifida is a spinal cord condition that occurs when the neural tube that forms the spinal cord and brain doesn't close completely during fetal development.¹ Severity of symptoms can vary, but patients may experience physical and learning disabilities as a result.¹ Babies born with spina bifida may also develop hydrocephalus, a condition where the baby has extra fluid in or around the brain, which can lead to brain swelling and further complications.² Advancements in anesthesia, aseptic surgical techniques, and approaches for improving neurologic complications have increased survival for patients with spina bifida.³ We sought to understand whether the median age at death in patients diagnosed with spina bifida has increased in recent years with these advancements.

We studied 3,541 patients diagnosed with spina bifida and 4,952,734 patients without a spina bifida diagnosis who died between 2011 and 2022 to determine the median age at death for each population. We found that the median age at death for patients with spina bifida increased 36.6%, from 41 years of age in 2011 to 56 years of age in 2022, as seen in Figure 1. The median age at death for patients without spina bifida stayed consistent, with a median of 75 years in both 2011 and 2022. In 2011, patients with spina bifida were living 34 fewer years than those without spina bifida. In 2022, the difference dropped to 19 years.

Median Age at Death for Patients with and Without Spina Bifida

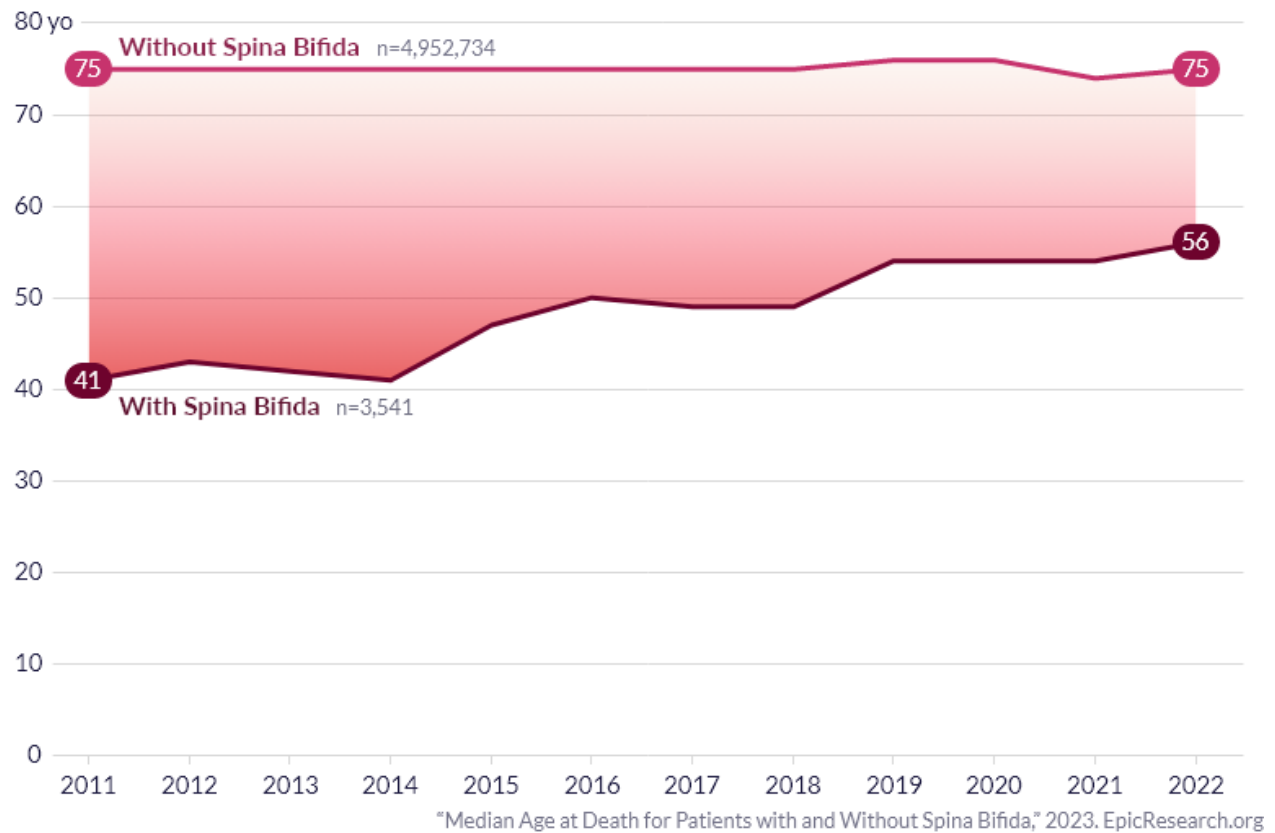
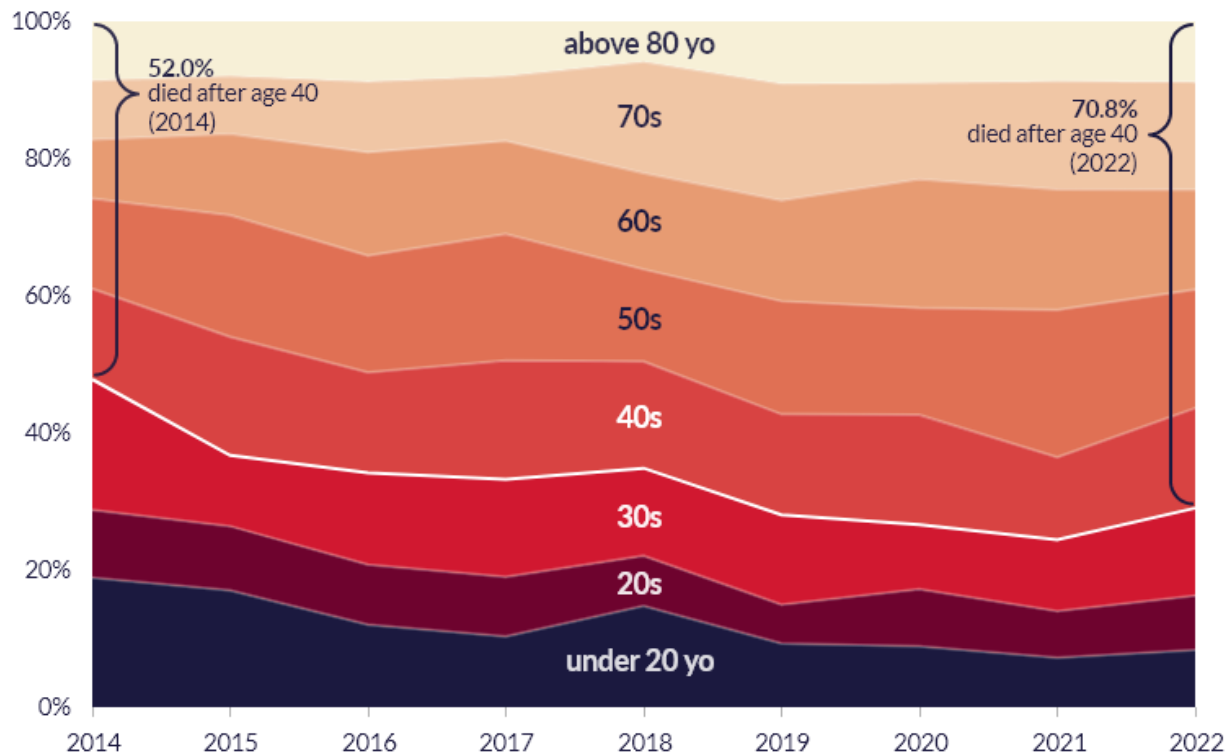


Figure 1. Median age at death for patients who died each year with and without spina bifida from 2011 to 2022.

We further stratified the age at death for patients with spina bifida each year to understand how the proportions of deaths in each decade of life have changed over time. In 2014, 52.0% of patients with spina bifida who died were 40 years of age or older. In 2022, that proportion increased to 70.8% of patients diagnosed with spina bifida who were at least 40 when they died.

Proportion of Annual Deaths by Age for Patients with Spina Bifida



n=3,297

"Proportion of Annual Deaths by Age for Patients with Spina Bifida," 2023. EpicResearch.org

Figure 2. Proportion of deaths for patients with spina bifida in each age group by year of death from 2014 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

1. CDC. What is Spina bifida? Centers for Disease Control and Prevention. <https://www.cdc.gov/ncbddd/spinabifida/facts.html>. Accessed August 18, 2023.
2. CDC. Spina bifida health issues and treatments. Centers for Disease Control and Prevention. <https://www.cdc.gov/ncbddd/spinabifida/treatment.html>. Accessed August 28, 2023.
3. Iskandar BJ, Finnell RH. Spina bifida. *The New England Journal of Medicine*, 2022;387(5), 444-450. <https://doi.org/10.1056/nejmra2116032>

Data Definitions

Term	Definition
Study period	2011-2022 (year of death)
Study population	Spina bifida diagnosis with ICD-10-CM code Q05.* Death date populated
Exposures	Year of death
Outcomes	Age of death in years

Table 1: Median Age at Death for Patients with and Without Spina Bifida

Year	Spina Bifida		No Spina Bifida	
	Age	Count	Age	Count
2011	41	42	75	136,780
2012	43	90	75	185,494
2013	42	112	75	231,787
2014	41	152	75	270,953
2015	47	203	75	309,313
2016	50	253	75	345,053
2017	49	266	75	410,914
2018	49	328	75	470,773
2019	54	389	76	527,163
2020	54	495	76	648,984
2021	54	592	74	707,930
2022	56	619	75	707,590

Table 2: Annual Deaths by Age for Patients with Spina Bifida

With Spina Bifida									
Age	2014	2015	2016	2017	2018	2019	2020	2021	2022
Under 20	29	35	31	28	49	37	45	44	53
20s	15	19	22	23	24	22	41	40	49
30s	29	21	34	38	42	51	47	62	79
40s	20	35	37	46	51	57	79	71	90
50s	20	36	43	49	44	64	77	127	107
60s	13	24	38	36	46	57	93	104	90
70s	13	17	26	25	53	66	69	93	97
Above 80	13	16	22	21	19	35	44	51	54