

Review

Cardiac Amyloidosis Trends in Relative Search Volume Data and Patient Safety

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Cardiac amyloidosis (CA), once considered a rare disease, is now being recognized more frequently by cardiologists. This is due in part to the improvement of diagnostic tools. Many patients with Transthyretin amyloid cardiomyopathy (ATTR-CM) travel long distances to a specialized center for the therapeutic interventions they need. This paper followed Doecker et al. (2023) specific formula for using google trends as a potential tool for predicting state demand. The Cardiologist Demand Index (CDI) for each state was developed. Based on the initial findings, states such as North Dakota, South Dakota, and Wyoming could benefit from opening Amyloidosis Treatment Centers in Academic Medical Centers. Amyloidosis Treatment Centers would benefit patients in these states due to the increase in public search inquiries (RSV data), access to clinical trials and research, and new treatments available to patients.

INTRODUCTION

Cardiac amyloidosis (CA), once considered a rare disease, is now being recognized more frequently by cardiologists. This is due in part to the improvement of diagnostic tools. According to Fontana et al. (2025), “Advances in cardiac imaging techniques have transformed the ability to diagnose, prognosticate, and treat patients with CA”.¹ The prevalence of CA has increased since there has been an improvement in diagnosis and survival rates. Specifically, over the past 12 years, cardiac amyloidosis went from 8 to 17 per 100,000 persons.² CA is now recognized as a frequent cause of heart failure and death. The prevalence of light chain (AL) amyloidosis is estimated to be 1 to 2 cases for every 100,000 people.³

There has also been a growing interest among physicians, scholars, and politicians on overall amyloidosis. On PubMed, there have been 10,596 publications related to Cardiac Amyloidosis, 5,147 of which were in the past 5 years (2020-2025).⁴ The most publications related to Cardiac Amyloidosis just occurred in 2024 – 1,030 publications. Also, the first bill to ever mention amyloidosis was presented to congress three times (2020, 2024, and 2025) - Dialysis-Related Amyloidosis Treatment Act.⁵ The bill has been bipartisan and co-sponsored by representatives in Texas, California, and New York.

Amyloidosis treatment centers are specialized treatment centers dedicated to the care of patients with amyloidosis. These facilities provide comprehensive diagnosis, treatment, care, and recovery services by offering access to multidisciplinary medical teams and state-of-the-art technology.⁶ In comparison to regular hospitals, amyloidosis care centers are considered more beneficial in caring for patients with amyloidosis due to the coordinated care amongst

many physicians that can make a unique and tailored treatment plan for individual patients.⁷ The patient centered approach of these treatment centers is a strong contributing factor to their success; when individual patient goals and quality-of-life are incorporated into treatment plans, patients are more likely to be engaged in their medical care, ultimately improving health outcomes.⁸ Beyond medical care, these facilities are also designed to provide holistic, individualized support, offering nutrition and social work services to all patients.

In 2021, Nativi-Nicolau et al. interviewed 15 Cardiologists that are at specialized Amyloidosis Centers in the United States, all of which belonged to an academic institution. There was a noticeable increase in new cardiac amyloidosis patients, especially those with ATTR-CM.⁷ The cardiologists surveyed attributed this rise to three main factors: greater physician awareness, new treatment options, and improved screening. Specifically, the use of radionuclide scans with PYP has made it easier to screen for and confirm a diagnosis of ATTR-CM. Vogel et al. (2024) presented an amyloidosis team that should be implemented by subspecialties in addition to cardiologists which include hematology, nephrology/gastroenterology, nuclear medicine/radiology, genetic counseling, heart failure nurses, and neurology. They argued that “An amyloidosis team with diverse specialties can help to coordinate tailored care and therapy and should be obligatory for amyloidosis centers.”⁹

Finally, many patients with Transthyretin amyloid cardiomyopathy (ATTR-CM) “went through multiple steps in order to find the therapeutic interventions they needed at a specialized center requiring long distance travel.”¹⁰ Due to the growing population of patients with cardiac amyloidosis, Phuyal & Bokhari (2024) argued that cardiac amyloidosis centers should be established in more community hos-

pitals. They stated that “Most of these patients are elderly, and it is difficult for these patients to travel long distances to academic amyloid centers”.¹¹ This led to the question of where there are gaps in amyloidosis treatment centers in the United States.

METHODS

This paper followed Doecker et al.'s (2023) specific formula for using google trends as a potential tool for predicting state demand.¹² Cardiac Amyloidosis was chosen over ATTR-CM or Amyloidosis since data on the number of cardiologists was accessible. On the other hand, there could be multiple specialists who treat patients with Amyloidosis. The number of cardiologists per state was divided by population per state to receive a score of cardiologist density per 10,000 citizens. Next, the google trends for “Cardiac Amyloidosis” was collected from September 2020 to September 2025 which is measured from 0 to 100, “the highest point on the graph for a given time and region is assigned a score of 100, representing the peak popularity for that term.”¹³ This would provide the relative search volume (RSV). Based on the recent literature on the growth of cardiac amyloidosis, google trends data from the past 5 years was appropriate to examine.

The Cardiologist Demand Index (CDI) for each state was determined. First, this was calculated by dividing the relative search volume (RSV) by its cardiologist density.¹⁴ Second, the Relative Cardiologist Demand Index (RCDI) was created by comparing how often people searched for “cardiac amyloidosis” on Google with how many cardiologists are available in each state. Third, this score is then scaled so that the state with the highest demand is set at 100, and all other states are shown relative to that. The RCDI was derived by normalizing each state's CDI relative to the highest observed value (North Dakota: 179.23), effectively creating a 0–100 scale for comparison. The formula for this specific model is stated below:

$$\text{Cardiac Amyloidosis Index}_{\text{State}} = \frac{\text{Relative Search Volume}_{\text{State}}}{\text{Cardiac Amyloidosis Density}_{\text{State}}}$$

States with Amyloidosis Treatment Centers, as listed by the Amyloidosis Foundation, an official 501c3, are used as supplemental support for the RCDI results in the discussion.¹⁵

RESULTS

Rhode Island and Massachusetts had the highest google score of 100. Meaning that “Cardiac Amyloidosis” experienced peak popularity within the 5-year time frame. We used the Amyloidosis Foundation list of “US Treatment Centers” in the literature to cross-reference accessibility of treatment to the scores. The google scores were not surprising given the fact that Massachusetts had 4 US Treatment Centers. Rhode Island is a neighboring state of Massachusetts as well and within driving distance to an amyloidosis treatment center. Next, Pennsylvania and Connecticut both received a score of 90. Both states also had amyloidosis treatment centers, 4 in Pennsylvania and 1 in Connecticut

respectively. Further, 3 states received an 81 google score – Vermont, Delaware, and New Hampshire, none of which had a US Treatment Center, but were in driving proximity to Massachusetts. The majority of the states had a 54 google score (15 states) or a 45 google score (14 states). 33 of the 50 states and Washington D.C. have US Amyloidosis Treatment Centers (Table One).

By calculating the RCDI, North Dakota had the highest score of 100. North Dakota has a population of 796,568 and 24 cardiologists. However, combined with the RSV search score for Cardiac Amyloidosis, which was a 54, the score increases. Even though there were 16 states with higher RSV searches, all the states had more cardiologists per state, where North Dakota only had 0.30 per 10,000 citizens. Major cities in North Dakota such as Fargo and Grand Forks are within driving range to neighboring Minnesota to the east which have an Amyloidosis Center. However, cities such as Bismarck which is closer to South Dakota and Minot which is closer to Montana do not have an Amyloidosis Center easily accessible.

South Dakota was the second highest score with an 81.94, also having an RSV score of 54 and a slightly higher cardiologist density of 0.37. Both states do not have an Amyloidosis Treatment Center. Utah had the third highest RCDI score of 77.85 and does have an Amyloidosis Treatment Center at the University of Utah. However, the southern tip of the state in St. George, Utah is still over 4 hours and 300 miles away. Wyoming was the 4th highest with a 76.98 score and also doesn't have an Amyloidosis Treatment Center. Rhode Island, which had the highest RSV of 100, was the 9th highest RCDI of 62.69% since they have a 0.89 cardiologist density score. If the density score were moved to 100,000 people, the rankings would remain the same. The average density would be 6.9 per 100,000. States like North Dakota (3.0) and Utah (3.2) are operating at densities below the ideal level for optimal patient outcomes.

DISCUSSION & CONCLUSION

Nativi-Nicolau et al. (2021) not only interviewed amyloidosis cardiologists as mentioned in the introduction, but they also interviewed patients.⁷ They also found that 31% of patients identified travel as their greatest challenge to accessing care at an amyloidosis center. A quarter of the patients had a one-way travel to an amyloidosis cardiology center that was only 30 minutes or less. However, 75% of patients were anywhere from 1 to over 5 hours (38% 1-2 hours, 13% 3-4 hours, and 25% 5 hours or more). According to Nativi-Nicolau et al., “traveling long distances was particularly problematic for patients with ATTR-CM and concomitant neuropathy. The physical demands of patients' travel were also potentially complicated by other commonly reported symptoms of their condition, such as decreased stamina, fluid overload, and shortness of breath.”⁷

Phuyal & Bukhari (2024) also argued that “as of 2022, only one FDA-approved disease-directed therapy, Tafamidis, is available for ATTR CA; thus, more CA (amyloidosis) centers are needed to provide a platform for ongoing and future clinical trials in this field”.¹¹ Since this article

Table One: The Cardiologist Demand Index (CDI)

State	Cardiologists Per State	State Population-2024	Cardiologist Density (Cardiologists per 10,000 people)	Google Score: Cardiac Amyloidosis: (9/17/20 - 9/17/25)	Amyloidosis Cardiologist Demand Index	Amyloidosis Relative Demand Index	Amyloidosis Centers by State
North Dakota	24	796,568	0.30	54	179.23	100.00	No
South Dakota	34	924,669	0.37	54	146.86	81.94	No
Utah	113	3,503,613	0.32	45	139.52	77.85	Yes
Wyoming	23	587,618	0.39	54	137.96	76.98	No
Wisconsin	351	5,960,975	0.59	72	122.28	68.22	Yes
Vermont	45	643,077	0.70	81	115.75	64.58	No
Idaho	80	2,001,619	0.40	45	112.59	62.82	Yes
Rhode Island	99	1,112,308	0.89	100	112.35	62.69	No
Washington	398	7,958,180	0.50	54	107.98	60.24	Yes
Alabama	273	5,157,699	0.53	54	102.02	56.92	No
Delaware	84	1,051,917	0.80	81	101.43	56.60	No
New Hampshire	113	1,409,032	0.80	81	101.00	56.35	No
Kansas	160	2,970,606	0.54	54	100.26	55.94	Yes
South Carolina	298	5,478,831	0.54	54	99.28	55.39	Yes
Kentucky	293	4,588,372	0.64	63	98.66	55.05	Yes
Hawaii	83	1,446,146	0.57	54	94.09	52.50	No
Pennsylvania	1309	13,078,751	1.00	90	89.92	50.17	Yes
Colorado	299	5,957,493	0.50	45	89.66	50.03	Yes
Minnesota	466	5,793,151	0.80	72	89.51	49.94	Yes
New Mexico	89	2,130,256	0.42	36	86.17	48.08	No
Georgia	705	11,180,878	0.63	54	85.64	47.78	Yes
Oregon	228	4,272,371	0.53	45	84.32	47.05	Yes
Virginia	565	8,811,195	0.64	54	84.21	46.99	No
Missouri	469	6,245,466	0.75	63	83.89	46.81	Yes
Arkansas	167	3,088,354	0.54	45	83.22	46.43	Yes
Maine	122	1,405,012	0.87	72	82.92	46.26	No
Montana	62	1,137,233	0.55	45	82.54	46.05	No
Mississippi	164	2,943,045	0.56	45	80.75	45.06	Yes
Tennessee	485	7,227,750	0.67	54	80.47	44.90	Yes
Alaska	33	733,391	0.45	36	80.01	44.64	No
Iowa	186	3,241,488	0.57	45	78.42	43.76	Yes
Connecticut	424	3,675,069	1.15	90	78.01	43.52	Yes
Illinois	880	12,710,158	0.69	54	77.99	43.52	Yes
Massachusetts	922	7,136,171	1.29	100	77.40	43.18	Yes
Arizona	443	7,582,384	0.58	45	77.02	42.97	Yes
Maryland	513	6,263,220	0.82	63	76.92	42.92	Yes
Ohio	978	11,883,304	0.82	63	76.55	42.71	Yes
Michigan	726	10,140,459	0.72	54	75.42	42.08	Yes
Indiana	438	6,924,275	0.63	45	71.14	39.69	Yes
Florida	1801	23,372,215	0.77	54	70.08	39.10	Yes
Nebraska	129	2,005,465	0.64	45	69.96	39.03	No

State	Cardiologists Per State	State Population-2024	Cardiologist Density (Cardiologists per 10,000 people)	Google Score: Cardiac Amyloidosis: (9/17/20 - 9/17/25)	Amyloidosis Cardiologist Demand Index	Amyloidosis Relative Demand Index	Amyloidosis Centers by State
North Carolina	725	11,046,024	0.66	45	68.56	38.25	Yes
Oklahoma	220	4,095,393	0.54	36	67.02	37.39	No
New Jersey	975	9,500,851	1.03	63	61.39	34.25	Yes
West Virginia	156	1,769,979	0.88	54	61.27	34.18	No
California	2416	39,431,263	0.61	36	58.76	32.78	Yes
Louisiana	355	4,597,740	0.77	45	58.28	32.52	Yes
Nevada	152	3,267,467	0.47	27	58.04	32.38	No
Texas	1646	31,290,831	0.53	27	51.33	28.64	Yes
New York	2490	19,867,248	1.25	63	50.27	28.05	Yes
District of Columbia	135	689,545	1.96	45	22.98	12.82	Yes

was published, Attruby (acoramidis) was also approved by the FDA at the end of 2024 (FDA, 2024). There is even more of a need to create more amyloidosis treatment centers to delivery therapy of ATTR CA (Maurer, 2025).¹⁶ Acoramidis has already been discussed in 25 publications on Pub Med in 2025.⁴

Based on the initial findings and prior literature (Nativi-Nicolau et al. (2021) Phuyal & Bukhari (2024), states such as North Dakota, South Dakota, and Wyoming could benefit from opening Amyloidosis Treatment Centers in Academic Medical Centers. North Dakota has grown by 18% in population since 2010 (672,591 in 2010 to 796,568 in 2024), making it one of the fastest growing states.¹⁷ Neighboring South Dakota and Wyoming are also growing in population size. Amyloidosis Treatment Centers would benefit patients in these states due to the increase in public search inquiries (RSV data), access to clinical trials and research, and new treatments available to patients.

This study had some of the same limitations as Doecker et. al. (2023). The data does not capture patients who find cardiologists who focus on amyloidosis via referral providers or alternative search engines. Similarly, we did not account for socioeconomic status, internet bias, health literacy, and government policy. Consequently, these findings may not fully reflect the nuanced barriers individuals face when accessing medical care. Finally, not all cardiologists have had patients with cardiac amyloidosis. According to Adam et. al. (2021), nearly three-quarters of the surveyed cardiologists (72%) indicated they had clinical experience treating cardiac amyloidosis patients.¹⁸

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