Identifying Patients with Cardiac Amyloidosis

Targeting rare disease patients with IQVIA's Patient Finder

Impact on healthcare

INSIGHT

- as a healthcare provider, using IQVIA's Patient Finder will enable you to better identify patients with a high probability for cardiac amyloidosis (ATTR-CM*) and call them in for further diagnostics;
- as a healthcare provider, it allows you to initiate the right treatment;
- increasing awareness of ATTR-CM improves the likelihood of correct diagnosis.

ASSURANCE

- in making the right diagnosis;
- for patients, there is greater certainty of receiving optimal treatment with fewer side effects and a better quality of life.

HEALTHCARE COSTS

- greater likelihood of the right diagnosis for the right patient and preventing misdiagnosis or underdiagnosis;
- potential reduction in costs for unnecessary treatments.

Challenge

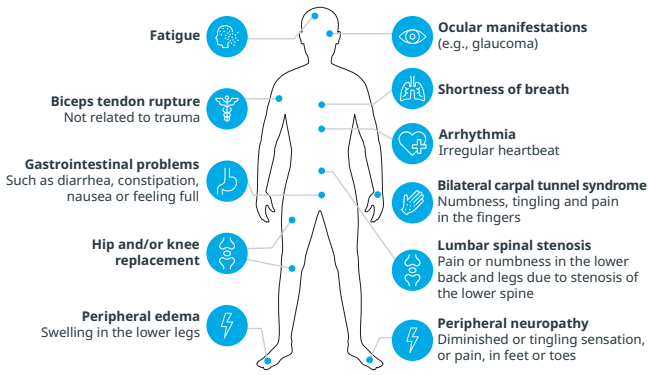
ATTR-CM is a potentially fatal disorder of the heart muscle that is rare and often undiagnosed or under-diagnosed. Due to this disease being relatively unknown, patients often receive misdiagnoses, do not receive appropriate care, have lower quality of life and increased mortality.[1]

Diagnosing amyloidosis is complicated; diverse symptoms are treated by different specialists without recognizing the interrelationship between them as a possible signal of ATTR-CM.

There is as yet no screening tool available to detect patients at risk of ATTR-CM in a structured, automated and efficient manner.

As cardiac amyloidosis becomes increasingly treatable, identifying these patients is also becoming increasingly important. Once patients suspected of having ATTR-CM are identified, specialized tests are required to actually confirm the diagnosis.

ATTR-CM is often accompanied by symptoms of heart failure, but there may also be other symptoms



Source: Heart Failure Society of America "http://www.hfsa.org"

The solution

Using IQVIA's Patient Finder technology, a search query was developed that allowed for the identification of potential ATTR-CM patients from the Electronic Patient Record (EPR) of a large hospital, enabling cardiologists to use additional diagnostics to diagnose ATTR-CM and begin appropriate treatment. First, the data from both structured fields and free text fields was organized within the EPR, then a search query found possible ATTR-CM patients in a way that adhered to all data privacy requirements.

The search query was refined several times through iteration and increasing understanding and based on characteristics and symptoms of already identified patients, literature, machine-learning and algorithms.

Patients with a high probability of ATTR-CM, such as those having a pacemaker, high protein levels or symptoms of heart failure, were recognized by using this algorithm. A search that, due to the variety of symptoms and multiple places in the EPR where the data was captured, would never be successful with a manual search.

Start of project (September 2021) → **Algorithm development** (October - November 2021) → **Algorithm adaptation** (November - December 2021) → **Research into specific patient cases** (December 2021 - April 2022) → **Results** (May 2022)

Search Strategy

1. **19,537 patients** with indications of hypertrophic cardiomyopathy (HCM) without aortic valve stenosis (AVS), > 50 years of age and alive
2. Of these 19,357 patients, **2,082 patients** also have HCM/Left Ventricular Hypertrophy (LVH)/Right Ventricular Hypertrophy (RVH) in their records
3. Of these 2,082 patients, **881 patients** have at least one risk factor
4. Of these 881 patients, **814 patients** have no previous cardiothoracic surgery to the aortic valve
5. Of these 814 patients, **774 patients** do not have a history of aortic valve stenosis
6. Of these 774 patients, **754 patients** do not have aortic valve stenosis as part of their care pathway
7. Of these 754 patients, **687 patients** do not have LVH/HCM excluded in the AI search criteria
8. Of these 687 patients, **601 patients** do not have RVH excluded in the AI search criteria
9. Of these 601 patients, **533 patients** do not have AVS presence in the AI examination criteria
10. Of these 533 patients, **53 patients** have 3 or more ATTR-CM specific risk factors

The outcome

Of the 19,537 patients older than 50 years with HCM and without AVS, there were 53 for whom the algorithm indicated strong evidence of ATTR-CM.

After checking with the cardiologist, a quarter of these were called up for further examination.

- **4 patients** turned out **actually** to have ATTR-CM
- **4 patients** had **no** ATTR-CM
- The remaining **6 patients** are **awaiting** further research or genetic testing

"The development of such an algorithm has the potential - as demonstrated at Haga Ziekenhuis - to detect patients at high risk of ATTR and thus enable treatment. This likely has a major impact on their clinical course and possible survival."

— Cardiologist

References and explanations of abbreviations
*ATTR-CM = Amyloid Transthyretin Cardiomyopathy or cardiac amyloidosis.
1. Maurer MS, Elliott P, Comenzo R, Semigran M, Rapezzi C. Addressing Common Questions Encountered in the Diagnosis and Management of Cardiac Amyloidosis. Circulation. 2017 Apr 4;135(14):1357-1377. doi: 10.1161/CIRCULATIONAHA.116.024438. PMID: 28373528; PMCID: PMC5392416.

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