The Profile of Transthyretin Amyloid Cardiomyopathy in Germany and Spain: A Real-World Survey of Cardiologists and Patients

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INTRODUCTION

- Transthyretin amyloid cardiomyopathy (ATTR-CM) is a progressive, life-threatening disease characterised by the accumulation of misfolded amyloid fibrils in the myocardial extracellular space.[1,2]
- There are two types of ATTR-CM: wild-type, which is associated with ageing, and variant ATTR-CM, caused by mutations in the transthyretin (*TTR*) gene.[2]
- Some patients with ATTR-CM also have polyneuropathy (ATTR-PN), characterised as mixed phenotype.[3]
- Currently, there is a lack of contemporary data on the clinical and sociodemographic characteristics of patients with ATTR-CM in the real world, which are needed to improve clinical management and treatment.
- Consequently, this study aimed to describe the characteristics and diagnostic journey of patients with ATTR-CM in Germany and Spain.

METHODS

Study objectives

- We evaluated the sociodemographic profile, disease characteristics and diagnostic pathway of real-world patients with ATTR-CM in Germany and Spain.

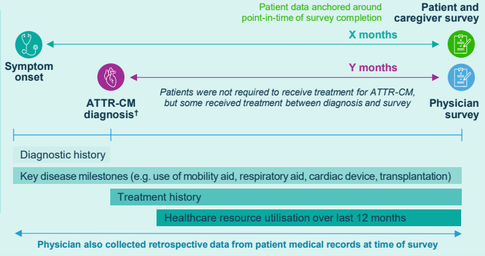
Study design

- This was a descriptive analysis of survey data from the Adelphi Real World ATTR I Disease Specific Programme (DSP)™, a cross-sectional survey of cardiologists and their consulting patients with ATTR-CM, with elements of retrospective data collection.[4] The study design is shown in **Figure 1**.
- Real-world survey data were collected within the context of routine care cardiology visits from September 2024 to January 2025.
- German and Spanish cardiologists treating at least one patient with ATTR-CM were invited to participate and enrol patients who were ≥18 years of age and had a confirmed diagnosis of ATTR-CM from a cardiologist.
- Each cardiologist completed electronic patient record forms for 1–10 consecutively consulted patients, including data on patients' sociodemographic profile, diagnostic characteristics, disease characteristics, treatment patterns and preferences, and healthcare resource utilisation.
- At the time of consultation, patients were invited to complete a voluntary paper-based patient survey, which included questions on patient characteristics, treatment, diagnostic history, health-related quality of life and symptoms.

Analysis

- Analyses were descriptive in nature. Sample statistics were reported using frequencies and percentages for categorical variables, and mean, standard deviation (SD), median, and range for numeric variables.
- Analyses were performed using Microsoft Excel and IBM® SPSS® Data Collection Survey Reporter v7.5.

Figure 1. Study overview



†Or diagnosis of mixed ATTR-CM/ATTR-PN phenotype.
ATTR-CM, transthyretin amyloid cardiomyopathy; ATTR-PN, transthyretin amyloid polyneuropathy.

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RESULTS

Study population

- A total of 61 cardiologists (Germany: 30, Spain: 31) provided data on 240 patients with ATTR-CM (Germany: 120, Spain: 120).
- In Germany, 70% of physicians were general cardiologists, and 30% were heart failure (HF) specialists. In Spain, 36% of physicians were general cardiologists, 58% were HF specialists, 3% were electrophysiologists and 3% were advanced imaging specialists.

Patient characteristics

- Sociodemographic and clinical characteristics are described in **Table 1**.
- The mean (SD) age of patients was higher in Spain, at 76 (11) years, than in Germany, at 67 (12) years. Overall, 22% of patients were female (Germany: 18%, Spain: 25%).

Characteristics of ATTR-CM

- In both countries, <7% of patients had a mixed phenotype (ATTR-PN as well as ATTR-CM).
- Among those with a known genotype (Germany: n=75, Spain: n=73), 64% had wild-type and 36% had hereditary ATTR-CM in Germany, and 71% had wild-type and 29% had hereditary ATTR-CM in Spain. ATTR-CM genotype was unknown for 38% of patients in Germany and 39% in Spain.
- The most common mutation was p.Val142Ile in Germany (n=10) and p.Val50Met in Spain (n=8).

Table 1. Sociodemographic and clinical characteristics of patients

Characteristics		All patients	Germany	Spain
Sample size	Patient count, n	240	120	120
Age, years	Mean (SD)	71.8 (12.4)	67.2 (12.0)	76.4 (11.0)
	Median (range)	73.0 (24.0–90.0)	70.0 (24.0–88.0)	79.0 (28.0–90.0)
Sex, n (%)	Female	52 (21.7)	22 (18.3)	30 (25.0)
	Male	188 (78.3)	98 (81.7)	90 (75.0)
Ethnicity, n (%)	White	231 (96.3)	115 (95.8)	116 (96.7)
	Black	5 (2.1)	2 (1.7)	3 (2.5)
	South Asian (Indian subcontinent)	1 (0.4)	1 (0.8)	0
	Middle Eastern or North African	2 (0.8)	2 (1.7)	0
	Other	1 (0.4)	0	1 (0.8)
Body mass index, kg/m²	Mean (SD)	26.0 (3.0)	25.7 (2.6)	26.4 (3.2)
	Underweight (<18.5), n (%)	0	0	0
	Normal (18.5–24.9), n (%)	96 (40.0)	55 (45.8)	41 (34.2)
	Overweight (25.0–29.9), n (%)	122 (50.8)	60 (50.0)	62 (51.7)
	Obese (≥30.0), n (%)	22 (9.2)	5 (4.2)	17 (14.2)
Phenotype, n (%)	ATTR-CM only	224 (93.3)	112 (93.3)	112 (93.3)
	Mixed phenotype (with ATTR-PN)	16 (6.7)	8 (6.7)	8 (6.7)
Genotype, n (%)	Hereditary	48 (20.0)	27 (22.5)	21 (17.5)
	Wild-type	100 (41.7)	48 (40.0)	52 (43.3)
	Not confirmed/unknown	92 (38.3)	45 (37.5)	47 (39.2)
NYHA functional class at survey, n (%)	I	27 (11.3)	11 (9.2)	16 (13.3)
	II	155 (64.6)	74 (61.7)	81 (67.5)
	III	54 (22.5)	34 (28.3)	20 (16.7)
	IV	4 (1.7)	1 (0.8)	3 (2.5)
Time since diagnosis, n (%)	<1 year	101 (42.1)	59 (49.2)	42 (35.0)
	≥1 to <2 years	65 (27.1)	27 (22.5)	38 (31.7)
	≥2 to <3 years	39 (16.3)	18 (15.0)	21 (17.5)
	≥3 to <4 years	13 (5.4)	7 (5.8)	6 (5.0)
	≥4 years	22 (9.2)	9 (7.5)	13 (10.8)
Reported tests used to confirm ATTR diagnosis, n (%)†	NT-proBNP	184 (80.0)	82 (74.5)	102 (85.0)
	Echocardiogram	186 (80.9)	84 (76.4)	102 (85.0)
	Heart biopsy	28 (12.2)	22 (20.0)	6 (5.0)
	Any biopsy	52 (22.6)	34 (30.9)	18 (15.0)
	Bone scintigraphy	76 (33.0)	35 (31.8)	41 (34.2)
	Cardiac scintigraphy	148 (64.3)	58 (52.7)	90 (75.0)
Number of comorbidities	Mean (SD)	2.5 (1.9)	2.1 (1.4)	2.8 (2.2)

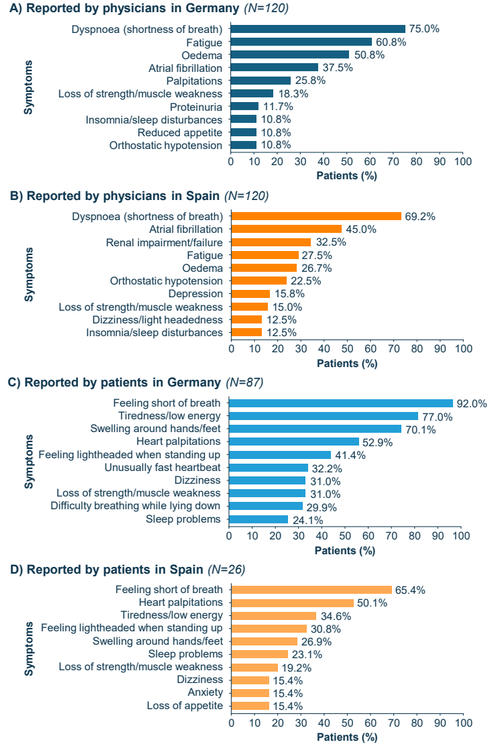
†n=110 for Germany (N=230 for all patients) as these data were unavailable for 10 patients. ATTR-CM, transthyretin amyloid cardiomyopathy; ATTR-PN, transthyretin amyloid polyneuropathy; NT-proBNP, N-terminal pro B-type natriuretic peptide; NYHA, New York Heart Association; SD, standard deviation.

- In both countries, the most common symptom at survey was dyspnoea, as reported by physicians (Germany: 75%; Spain: 69%) and patients (Germany: 92%; Spain: 65%) (**Figure 2**).

Comorbidities

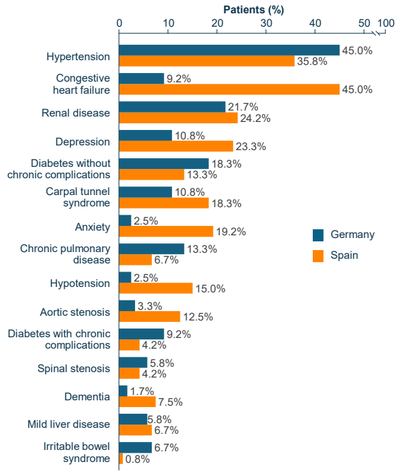
- Patients had a mean (SD) of 2.1 (1.4) comorbidities in Germany and 2.8 (2.2) in Spain. The most common comorbidity was hypertension in Germany (45%) and congestive HF in Spain (45%) (**Figure 3**).

Figure 2. Most commonly reported symptoms at survey



Overall, 89 patients from Germany completed the self-reported survey; however, two patients did not provide data on their current symptoms; 29 patients from Spain completed the self-reported survey, but three did not provide data on their current symptoms.

Figure 3. Proportion of patients with comorbidities in Germany and Spain



Diagnostic journey

- Most patients were first diagnosed with ATTR-CM within the year prior to survey (Germany: 49%, Spain: 35%) or within 1–2 years prior to survey (Germany: 23%, Spain: 32%).
- Among patients with available data, mean (SD) time from symptom onset to ATTR diagnosis was 7 (15) months in Germany and 24 (24) months in Spain.
- According to information available in each patient's chart at the time of data collection, most patients received a biopsy or scintigraphy at the time of diagnosis (Germany: 87%, Spain: 92%).
- On average, 81% of patients reported challenges receiving a diagnosis (Germany: 78%, Spain: 93%). In Germany, the most frequent reasons were misdiagnosis (52%) and long wait times for specialist visits (41%). In Spain, the most common reasons were long wait times for test results (41%) and specialist visits (37%), and difficulty getting referred to specialist doctors (37%).

CONCLUSIONS

- Less than 7% of patients had mixed phenotype, and 20% had a known *TTR* mutation.
- The majority of patients had mild–moderate symptoms that could benefit from disease-modifying therapy.
- Differences in time from symptom onset to diagnosis are suggestive of unmet diagnostic needs, reflecting possible nuances in healthcare systems, and the importance of continual efforts to increase disease awareness among cardiologists and other healthcare providers.
- Given that the data used in this study come from physician and patient surveys and are not representative of population-level real-world data sources, the findings from this study may not be generalisable to all settings.
- Further studies should evaluate possible associations between high levels of ATTR-CM comorbidities (e.g. carpal tunnel syndrome) and delays in diagnosis and treatment of new ATTR-CM patients, particularly in Spain.