Caregiver Burden by Severity of Patient's Heart Failure due to Transthyretin Amyloid Cardiomyopathy: Results From a Large, Non-Interventional, Real-World Study

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INTRODUCTION

- Transthyretin amyloid cardiomyopathy (ATTR-CM) is a condition that causes progressive heart failure.[1] The symptoms associated with ATTR-CM can be limiting on the daily activities of patients.[2]
- Primary caregivers provide vital support to patients with ATTR-CM, but few studies have aimed to characterize the burden of ATTR-CM on them.[2,3]
- This multicenter, international, real-world survey aimed to comprehensively evaluate the burden of ATTR-CM on caregivers to patients untreated with disease-modifying treatment. It further aimed to explore this burden in caregivers to patients with different severities of heart failure symptoms.[4]

METHODS

- This large, cross-sectional, noninterventional study recruited pairs of patients with ATTR-CM and their unpaid primary caregivers from international amyloidosis centers of excellence and referral centers between July 2021 and August 2022.[4]
  - Caregivers and patients must have been 18–89 years old.
  - Patients were naïve to disease-modifying therapy, had not had a heart or liver transplant, or a left ventricular mechanical assist device, but could have been receiving symptomatic standard of care therapy.
  - Caregivers could not join the study if they had ATTR-CM themselves, or any other disease that significantly impacted their perceived quality of life.
- Caregivers completed surveys on various aspects of disease burden, including on the tasks that patients required help with, and the impact of caregiving on their daily life.
- Caregivers also completed the 22-item Zarit Burden Interview (ZBI), which is scored over a range from 0 to 88, where a higher score indicates a higher caregiver burden.[5]
  - Burden was interpreted as: 0 to 20 = little or no burden, 21 to 40 = mild to moderate burden, 41 to 60 = moderate to severe burden, and 61-88 = severe burden.
- The recruiting investigator reported on the patient's New York Heart Association (NYHA) functional classification, and the caregiver's age, sex, and underlying conditions.
- Findings were summarized descriptively for the overall caregiver population and by caregivers to patients with NYHA class I/II or III heart failure symptoms. No statistical analyses were performed.

RESULTS

- 208 patient and caregiver pairs from Europe, Australia, Canada, and Russia were recruited to the study and provided responses.
- Patients were a median age of 81 years (range: 46–90 years), 86% were male, and 91% of those with genetic testing data had wild-type ATTR-CM (n=141/155).
  - Over two-thirds (78%; n=156/199) of patients with NYHA classifications were class I/II, and the remaining were class III (22%; n=43/199).
  - The median time since diagnosis was 6 months (interquartile range [IQR]: 0.1–1.3; n=207).
- Caregivers were a median age of 68 years, 85% were female, and 66% lived with the patient they cared for (**Table 1**).
  - They were usually the spouse (59%) or adult child (37%) of the patient.
  - The median duration of caregiving was 1.5 years, suggesting that caregivers had provided care for approximately 1 year prior to diagnosis.

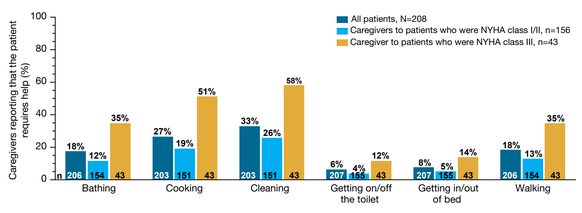
Table 1: Demographics and characteristics

	Caregivers N=208	Caregivers to patients who were NYHA class I/II n=156	Caregivers to patients who were NYHA class III n=43
Age, median (min, max), y	68.0 (32, 88)	68.5 (32, 88)	68.0 (45, 83)
Sex, n (%)			
Male	32 (15.4)	25 (16.0)	4 (9.3)
Female	176 (84.6)	131 (84.0)	39 (90.7)
Relationship to patient, n (%)			
Spouse	122 (58.7)	95 (60.9)	26 (60.5)
Child	77 (37.0)	56 (35.9)	14 (32.6)
Parent	2 (1.0)	1 (0.6)	1 (2.3)
Sibling	1 (0.5)	1 (0.6)	0
Other	6 (2.9)	3 (1.9)	2 (4.7)
Caregiver and patient live in the same house, n (%)	138 (66.3)	102 (65.4)	34 (79.1)
Years caregiving to date, median (IQR)	1.5 (0.0–3.0)[a]	1.0 (0.0–3.0)[b]	2.0 (1.3–3.5)[c]

[a]n=166, [b]n=123, [c]n=37.
IQR=interquartile range; max=maximum; min=minimum; NYHA=New York Heart Association

- Caregivers reported that patients required help with a wide range of daily activities (**Figure 1**).
  - The proportion of patients requiring help with each task was higher among those who were NYHA class III vs I/II.

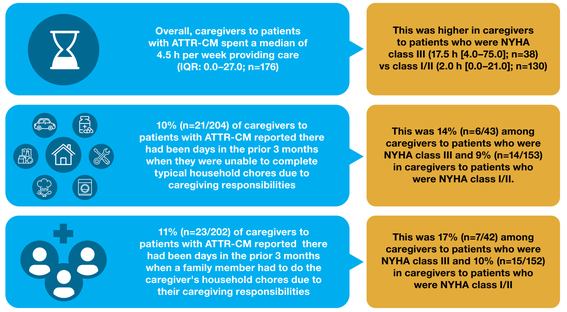
Figure 1: Tasks that patients required help with



Nine patients did not have a recorded NYHA classification and are not included in the subgroups.
NYHA=New York Heart Association

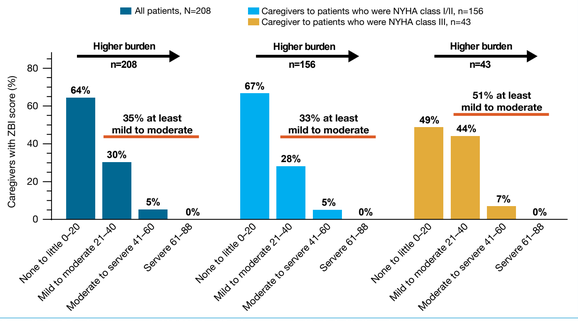
- Caregivers provided care for a median of 4.5 hours each week. Some reported that their caregiving responsibilities had prevented them completing typical household tasks (**Figure 2**).
  - The number of hours spent providing care each week and the proportion of caregivers who were not able to complete their household tasks was higher among those caring for patients who were NYHA class III vs I/II.
- The median ZBI score among caregivers to patients with ATTR-CM was 13 (IQR: 3.0–24.0), indicating a little burden.
  - This was 21 (5.0–27.0) in caregivers to patients who were NYHA class III, suggesting a mild to moderate burden and 14 (4.0–23.5) in caregivers to patients who were NYHA class I/II, suggesting little burden.
- 35% of all caregivers to patients with ATTR-CM had a ZBI score indicating at least a mild to moderate burden of care (**Figure 3**).
  - 51% of caregivers to patients who were NYHA class III and 33% of caregivers to patients who were NYHA class I/II reported at least a mild to moderate burden of care.

Figure 2: Limitations of caregiving



Nine patients did not have a recorded NYHA classification and are not included in the subgroups.
ATTR-CM=transthyretin amyloid cardiomyopathy; NYHA=New York Heart Association

Figure 3: Categorical burden



Nine patients did not have a recorded NYHA classification and are not included in the subgroups.
NYHA=New York Heart Association; ZBI=Zarit Burden Interview

Limitations

- Interpretation of the findings is based on observed numerical differences and should not be extrapolated outside the caregiver and patient populations surveyed. All patients were untreated with disease-modifying therapy, and most were relatively newly diagnosed with wild-type ATTR-CM. The extent and character of the burden felt by caregivers may change over time, as caregiving continues over a longer duration and the patient's ATTR-CM progresses.

CONCLUSION

- This large, multinational, real-world study demonstrated that ATTR-CM is a burden on caregivers to patients with ATTR-CM that are untreated with disease-modifying therapy.[4]
- Caregivers reported that patients required help with a wide range of daily activities, and some said that their responsibilities prevented them from doing their own daily activities.
  - Over a third of all caregivers reported at least a mild to moderate burden of care.
- Our ZBI findings indicate a lower burden than previously reported, but this likely reflects differences in the caregiver and patient populations evaluated (eg, caregiver characteristics, duration of caregiving, patient's disease severity, and societal values).[3]
- Measures of burden appeared to be higher in caregivers to patients with more advanced heart failure symptoms.

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DISCLOSURES

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