Supplementary Material

The Burden of Transthyretin Amyloid Cardiomyopathy on Caregivers and Patients in Japan: A Cross-Sectional Real-World Survey

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Supplementary Table 1. Physician characteristics

	Overall n=25
Physician specialty, n (%)	
General cardiologist	21 (84.0)
Heart failure specialist	3 (12.0)
Electrophysiologist	1 (4.0)
Practice setting, n (%)	
Academic hospital	12 (48.0)
Community hospital	16 (64.0)
Office	7 (28.0)
Number of patients managed by physician, mean (SD)	
ATTR-CM	12.9 (16.7)
ATTR-PN	1.7 (4.1)
ATTR-CM + ATTR-PN	1.2 (2.2)

Abbreviations: ATTR-CM, transthyretin amyloidosis cardiomyopathy; ATTR-PN, transthyretin amyloidosis polyneuropathy

Supplementary Table 2. Physician-reported patient characteristics by the patient's NYHA class

	Overall	NYHA I	NYHA II	NYHA III+
	n=106	n=26	n=65	n=15
Employment status, n (%)				
Retired	71 (67.0)	13 (50.0)	46 (70.8)	12 (80.0)
Homemaker	17 (16.0)	5 (19.2)	10 (15.4)	2 (13.3)
Working full-time	11 (10.4)	5 (19.2)	5 (7.7)	1 (6.7)
Working part-time	3 (2.8)	1 (3.8)	2 (3.1)	0 (0.0)
Unemployed	2 (1.9)	1 (3.8)	1 (1.5)	0 (0.0)
On long-term sick leave	1 (0.9)	0 (0.0)	1 (1.5)	0 (0.0)
On short-term sick leave	1 (0.9)	1 (3.8)	0 (0.0)	0 (0.0)
ATTR phenotype, n (%)	n=120	n=32	n=70	n=18
ATTR-CM	112 (93.3)	31 (96.9)	64 (91.4)	17 (94.4)
ATTR-CM + ATTR-PN	8 (6.7)	1 (3.1)	6 (8.6)	1 (5.6)
Time since amyloidosis diagnosis (years)				
Median (Q1, Q3)	1.3 (0.6, 2.2)	1.0 (0.5, 1.8)	1.4 (0.6, 2.3)	1.7 (0.7, 2.7)
Prescribed treatment for ATTR amyloidosis symptoms, n (%)				
Yes (any treatment)	104 (86.7)	29 (90.6)	61 (87.1)	14 (77.8)
Prescribed a DMT	99 (82.5)	28 (87.5)	59 (84.3)	12 (66.7)
No, but has been previously	2 (1.7)	0 (0.0)	1 (1.4)	1 (5.6)
No, and has never received prescribed treatment	14 (11.7)	3 (9.4)	8 (11.4)	3 (16.7)

Abbreviations: ATTR, transthyretin amyloidosis; CM, cardiomyopathy; NYHA, New York Heart Association; PN, polyneuropathy; SD, standard deviation; Q1, quartile 1; Q3, quartile 3; DMT, disease modifying therapy

Supplementary Table 3. Caregiver ZBI scores

	Mean (SD)
Overall ZBI score	38.3 (19.3)
ZBI domain scores	
Guilt	3.9 (2.3)
Burden in the relationship	10.0 (4.3)
Emotional wellbeing	11.3 (5.6)
Social and family life	7.1 (4.5)
Finances	2.0 (1.2)
Loss of control over one's life	8.0 (4.3)
Personal strain	18.9 (9.3)
Role strain	10.7 (6.3)

Abbreviations: SD, standard deviation; ZBI, Zarit Burden Interview

ZBI total scores range from 0 to 88, with higher scores indicating greater caregiver burden. Domain scores represent sums of item responses and are derived from overlapping (non-mutually exclusive) item groupings. Personal strain reflects overall emotional burden, and role strain reflects the impact of caregiving on personal roles and responsibilities.

Supplementary Table 4. KCCQ summary and domain scores

	n	Mean (SD)
KCCQ domains		
Quality of Life	32	64.1 (22.9)
Social Limitation	28	71.6 (26.6)
Physical Limitation	22	68.6 (23.4)
Total Symptom Score*	32	79.4 (20.9)
Symptom Frequency	32	78.8 (22.1)
Symptom Burden	32	79.9 (20.8)
Self-Efficacy	32	68.8 (22.5)
Symptom Stability	30	51.7 (18.5)
KCCQ summary scores		
Clinical Summary Score**	22	71.6 (16.6)
Overall Summary Score***	20	65.1 (17.4)

Abbreviations: KCCQ, Kansas City Cardiomyopathy Questionnaire; SD, standard deviation.

KCCQ scores range from 0 to 100, with higher scores indicating better health status. Composite scores represent averages of specific domains:

*Total Symptom Score is calculated as the average of the symptom frequency and symptom burden domains.

**Clinical Summary Score is calculated as the average of the physical limitation and total symptom scores.

***Overall Summary Score is calculated as the average of the physical limitation, total symptom score, quality of life, and social limitation domains.