

Impact of Disease Progression on Healthcare Resource Utilization and Quality of Life in Patients With Hypertrophic Cardiomyopathy: A Real-World Cross-Sectional Survey

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INTRODUCTION AND OBJECTIVE

- Hypertrophic cardiomyopathy (HCM) is a chronic, progressive disease characterized by left ventricular hypertrophy.^{1,2}
- Several studies have reported that HCM is associated with substantial medical costs and decline in quality of life (QoL).³⁻⁶ Most of these studies focused on obstructive HCM (oHCM) whereas data on non-obstructive HCM (nHCM) is limited.⁷
- Evidence linking Kansas City Cardiomyopathy Questionnaire (KCCQ) scores to outcomes in HCM remains limited.
- Our study evaluated the effect of disease progression on healthcare resource utilization (HCRU) and QoL in patients with HCM according to:
 - KCCQ-Clinical Summary Score (KCCQ-CSS) quartiles.
 - Current New York Heart Association (NYHA) functional classification.

METHODS

Study Design and Data

- Data were drawn from the Adelphi Real World HCM Disease Specific Programme, a multinational, cross-sectional survey conducted between July 2022 and October 2024 in Italy, Spain, and the United States (US).
- The DSP methodology details were previously described, validated, and demonstrated to be representative and consistent over time.⁸⁻¹⁰
- Cardiologists completed a questionnaire that included demographics, HCM severity via NYHA and HCRU for their patients with HCM, and patients completed the EuroQol 5-Dimension 5-Level (EQ-5D-5L) questionnaire and KCCQ.

Statistical Analysis

- The cohort was analyzed according to NYHA functional class (I–IV), with higher classes indicating greater functional limitations and more severe symptoms.
- The analysis was repeated using KCCQ-CSS quartiles (Q) as a measure of disease progression and defined as: Q1: >0–≤70, Q2: >70–≤83, Q3: >83–≤92, and Q4: >92–≤100.
 - KCCQ-CSS scores are reported on a point scale of 0–100, where lower scores indicate more severe symptoms and limitations and a score of 100 represent no symptoms or limitations.
- Patient characteristics and comparisons across groups were conducted using analysis of variance, chi-squared, Fisher's exact, or t-tests (*P*<0.05 considered significant). Spearman's rank assessed associations between disease progression, HCRU, and EQ-5D-5L.

Outcomes

- Mean (SD) for HCRU in the last 12 months and QoL (EQ-5D-5L; US value set) were reported for each NYHA class and KCCQ quartiles.
 - HCRU included: HCM-related hospitalizations, emergency room (ER) visits, day visits, and caregiver support.

RESULTS

- Demographics and characteristics for all patients (N=1909) are shown in **Table 1**.
- Characteristics according to HCM phenotype (oHCM or nHCM) and region (US and Europe) are presented in **Supplementary Tables* 1–2**.
- Of 1909 patients, mean age was 56.48 years and 60.71% were male.
- KCCQ-CSS and NYHA class, respectively, were available for 286 and 1909 patients with HCM.

*Scan the QR code to access the supplementary material.

HCRU and QoL

- Overall, patients in higher NYHA class and those with lower KCCQ-CSS had increased HCRU and decreased QoL (**Figures 1–2, Tables 2–3**).
- Results by HCM phenotype (oHCM or nHCM) and region (US or Europe) were broadly consistent with the overall population, reflecting increased HCRU and decreased QoL for patients with higher NYHA class and lower KCCQ-CSS (**Supplementary Tables 3–6**).

Limitations

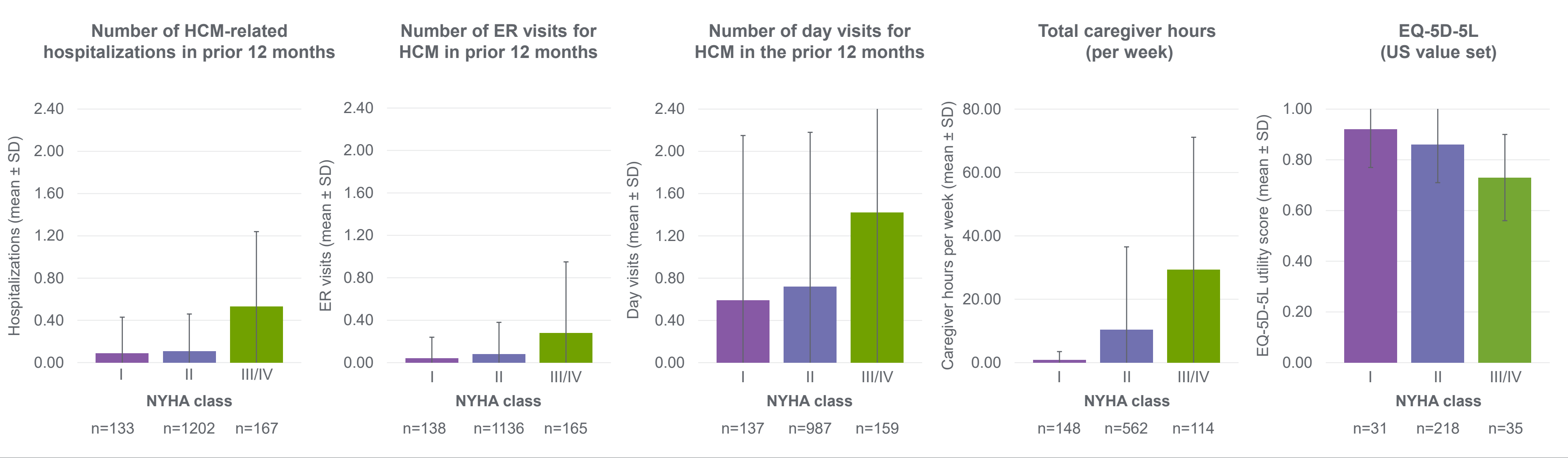
- Data from the survey are cross-sectional, with limited information about individual patient journeys or disease trajectory.
- Participation is affected by the willingness to complete the survey and may not reflect a random sample of cardiologists or patients with HCM.

Table 1. Patient demographics and characteristics for the overall population

n (%) ^a	All patients with HCM N=1909	n (%) ^a	All patients with HCM N=1909
Age, years		CV comorbidities	
Mean ± SD	56.48 ± 14.79	Hypertension	610 (31.95)
Biological sex		Atrial fibrillation/flutter	375 (19.64)
Male	1159 (60.71)	Hyperlipidemia	280 (14.67)
Female	750 (39.29)	Left atrial dilation	168 (8.80)
Region		Heart failure	138 (7.23)
Italy	608 (31.85)	Non-sustained ventricular tachycardia	109 (5.71)
Spain	600 (31.43)	Current NYHA classification	
US	701 (36.72)	Class I	157 (8.22)
Employment status	n=1833	Class II	1494 (78.26)
Working full time	831 (45.34)	Class III/IV	258 (13.51)
Not working due to retirement	602 (32.84)		
Working part time	127 (6.93)		
Homemaker	123 (6.71)		
Unemployed	81 (4.42)		
Student	43 (2.35)		
On long-term sick leave	26 (1.42)		

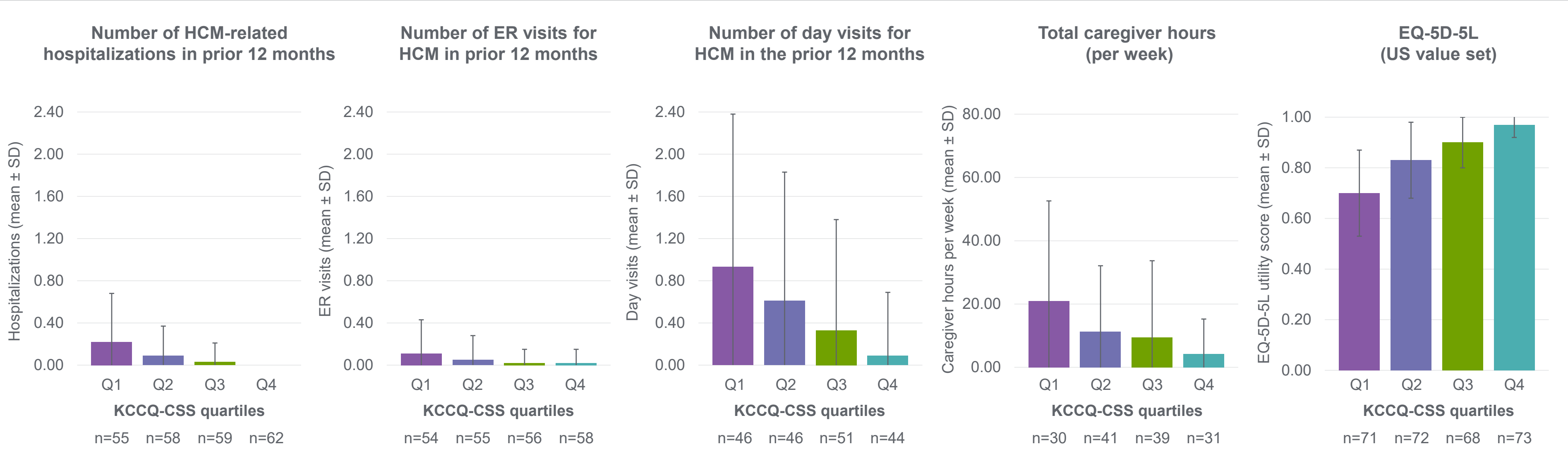
^a Unless otherwise indicated.
CV, cardiovascular; NYHA, New York Heart Association; SD, standard deviation.

Figure 1. HCRU and QoL by NYHA class in the overall population



Data are mean ± SD.
EQ-5D-5L, EuroQol 5-Dimension 5-Level; ER, emergency room; HCM, hypertrophic cardiomyopathy; HCRU, healthcare resource utilization; NYHA, New York Heart Association; QoL, quality of life; SD, standard deviation.

Figure 2. HCRU and QoL by KCCQ-CSS quartile in the overall population



Data are mean ± SD. Q1: >0 to ≤70; Q2: >70 to ≤83; Q3: >83 to ≤92; and Q4: >92 to ≤100.
EQ-5D-5L, EuroQol 5-Dimension 5-Level; ER, emergency room; HCM, hypertrophic cardiomyopathy; HCRU, healthcare resource utilization; KCCQ-CSS, Kansas City Cardiomyopathy Questionnaire–Clinical Summary Score; Q, quartile; QoL, quality of life; SD, standard deviation.

Table 2. HCRU and QoL by NYHA class in the overall population

	NYHA class I		NYHA class II		NYHA class III/IV		P-value
	n=157	Mean (SD)	n=1494	Mean (SD)	n=258	Mean (SD)	
Number of HCM-related hospitalizations in the last 12 months	n=133	0.09 (0.34)	n=1202	0.11 (0.35)	n=167	0.53 (0.71)	<0.0001
Number of HCM-related ER visits in the last 12 months	n=138	0.04 (0.20)	n=1136	0.08 (0.30)	n=165	0.28 (0.67)	<0.0001
Number of HCM-related day visits in the last 12 months	n=137	0.59 (1.56)	n=987	0.72 (1.46)	n=159	1.42 (1.92)	<0.0001
Total caregiver hours per week	n=148	0.78 (2.72)	n=562	10.39 (26.15)	n=114	29.36 (41.76)	<0.0001
EQ-5D-5L (US value set)	n=31	0.92 (0.15)	n=218	0.86 (0.15)	n=35	0.73 (0.17)	<0.0001

EQ-5D-5L, EuroQol 5-Dimension 5-Level; ER, emergency room; HCM, hypertrophic cardiomyopathy; HCRU, healthcare resource utilization; NYHA, New York Heart Association; QoL, quality of life; SD, standard deviation.

Table 3. HCRU and QoL by KCCQ-CSS quartile in the overall population

	Q1 (>0 to ≤70)		Q2 (>70 to ≤83)		Q3 (>83 to ≤92)		Q4 (>92 to ≤100)		P-value
	n=72	Mean (SD)	n=72	Mean (SD)	n=69	Mean (SD)	n=73	Mean (SD)	
Number of HCM-related hospitalizations in the last 12 months	n=55	0.22 (0.46)	n=58	0.09 (0.28)	n=59	0.03 (0.18)	n=62	0.00 (0.00)	<0.0001
Number of HCM-related ER visits in the last 12 months	n=54	0.11 (0.32)	n=55	0.05 (0.23)	n=56	0.02 (0.13)	n=58	0.02 (0.13)	0.0140
Number of HCM-related day visits in the last 12 months	n=46	0.93 (1.45)	n=46	0.61 (1.22)	n=51	0.33 (1.05)	n=44	0.09 (0.60)	<0.0001
Total caregiver hours per week	n=30	20.97 (31.62)	n=41	11.29 (20.81)	n=39	9.46 (24.22)	n=31	4.23 (11.03)	<0.0001
EQ-5D-5L (US value set)	n=71	0.70 (0.17)	n=72	0.83 (0.15)	n=68	0.90 (0.10)	n=73	0.97 (0.05)	<0.0001

EQ-5D-5L, EuroQol 5-Dimension 5-Level; ER, emergency room; HCM, hypertrophic cardiomyopathy; HCRU, healthcare resource utilization; KCCQ-CSS, Kansas City Cardiomyopathy Questionnaire–Clinical Summary Score; Q, quartile; QoL, quality of life; SD, standard deviation.

CONCLUSIONS

- In patients with HCM, HCRU increased and QoL deteriorated with disease progression, as measured by NYHA class and KCCQ-CSS.
- Effective treatments that help lower HCRU and improve QoL are needed to reduce the economic and humanistic burden of HCM for patients and healthcare systems.

Disclosures

PG, MB and SS are employees of and hold stock in Cytokinetics, Incorporated. JJ, LH, LL, EG and SB are employees of Adelphi Real World. KA has nothing to disclose. YJS has received funding from Bristol Myers Squibb and consulting from Bristol Myers Squibb and Moderna Japan.

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