

Describing the Role of Caregivers in ATTR-CM: A Secondary Analysis of Survey Data From Germany and Spain



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INTRODUCTION

- Transthyretin amyloid cardiomyopathy (ATTR-CM) is a serious, progressive heart disease in which amyloid fibrils accumulate in the myocardial extracellular space, which can cause heart failure and death if left untreated.^{1,2}
- ATTR-CM predominantly affects elderly patients.¹ Thus, many patients with ATTR-CM may require caregiving support over the course of their disease.
- There are limited real-world data on the role of caregivers in supporting patients with ATTR-CM and the impact on caregivers' quality of life, owing to the challenges of obtaining these insights.

METHODS

Study objectives

- Our study investigated the roles, responsibilities, and burdens experienced by caregivers supporting patients with ATTR-CM in Germany and Spain.

Study design

- This was a descriptive, secondary analysis of data from the Adelphi Real World ATTR 1 Disease Specific Programme (DSP)TM, a cross-sectional survey of cardiologists, their consulting patients with ATTR-CM, and their caregivers, which included elements of retrospective data collection.³
- German and Spanish cardiologists treating ≥1 patient with ATTR-CM were asked to fill out a Patient Record Form (PRF) for 1–10 consecutively consulted patients aged ≥18 years with a confirmed diagnosis of ATTR-CM. Data were collected within the context of routine care visits from September 2024 to January 2025.

- Patients and non-professional caregivers in attendance during routine care visits were asked to complete voluntary surveys covering information on their characteristics, health-related quality of life (HRQoL), and daily tasks. Caregivers were also asked to complete the EuroQol 5-dimension (EQ-5D) and EuroQol visual analogue scale (EQ-VAS) questionnaires.^{4,5}

Analysis

- Results were descriptively reported and stratified by country. Sample statistics were reported using frequencies and percentages (categorical variables), or mean, standard deviation (SD), median, and range (numeric variables). HRQoL was assessed based on validated instruments (EQ-5D and EQ-VAS) and descriptive reporting of other questions in the DSP.
- Analyses were performed using Microsoft Excel and UNICOM[®] Intelligence Reporter v7.5.

RESULTS

Study population

- Cardiologists (Germany: n=30, Spain: n=31) provided medical histories for 120 patients in each country. Optional surveys were completed by 89 patients and 32 caregivers in Germany, and 29 patients and 18 caregivers in Spain.
- The mean (SD) age of caregivers (who completed a voluntary survey) was 65 (9) years in Germany and 68 (13) years in Spain; most caregivers were female (Germany: 88%; Spain: 78%) (Table 1).

Table 1. Demographics and characteristics of caregivers who completed a voluntary survey

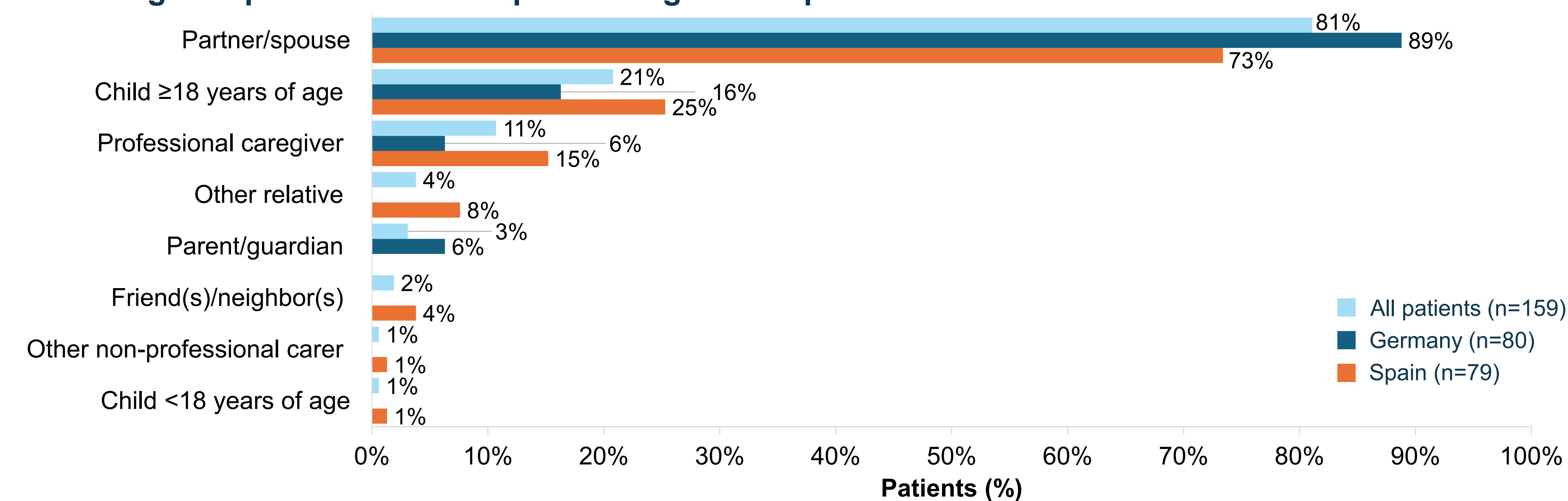
| | All caregivers (N=50) | Germany (n=32) | Spain (n=18) |
|-----------------------------------------------------------------------------------|-----------------------|-------------------|-------------------|
| Sex, n (%) | | | |
| Male | 8 (16.0) | 4 (12.5) | 4 (22.2) |
| Female | 42 (84.0) | 28 (87.5) | 14 (77.8) |
| Age, years | | | |
| Mean (SD) | 66.0 (10.6) | 64.9 (8.8) | 67.9 (13.4) |
| Median (min, max) | 68.5 (41.0, 87.0) | 68.0 (41.0, 75.0) | 71.0 (42.0, 87.0) |
| Caregivers with health problems making it difficult to provide care, n (%) | 6 (12.0) | 3 (9.4) | 3 (16.7) |
| Caregivers living with the patient, n (%) | | | |
| Yes | 41 (82.0) | 25 (78.1) | 16 (88.9) |
| No | 9 (18.0) | 7 (21.9) | 2 (11.1) |
| Time spent caregiving per week, hours | | | |
| Mean (SD) | 36.1 (36.1) | 31.4 (17.6) | 45.6 (57.5) |
| Min, max | 2.0, 168.0 | 2.0, 60.0 | 2.0, 168.0 |

max, maximum; min, minimum; SD, standard deviation.

Caregiver roles and responsibilities

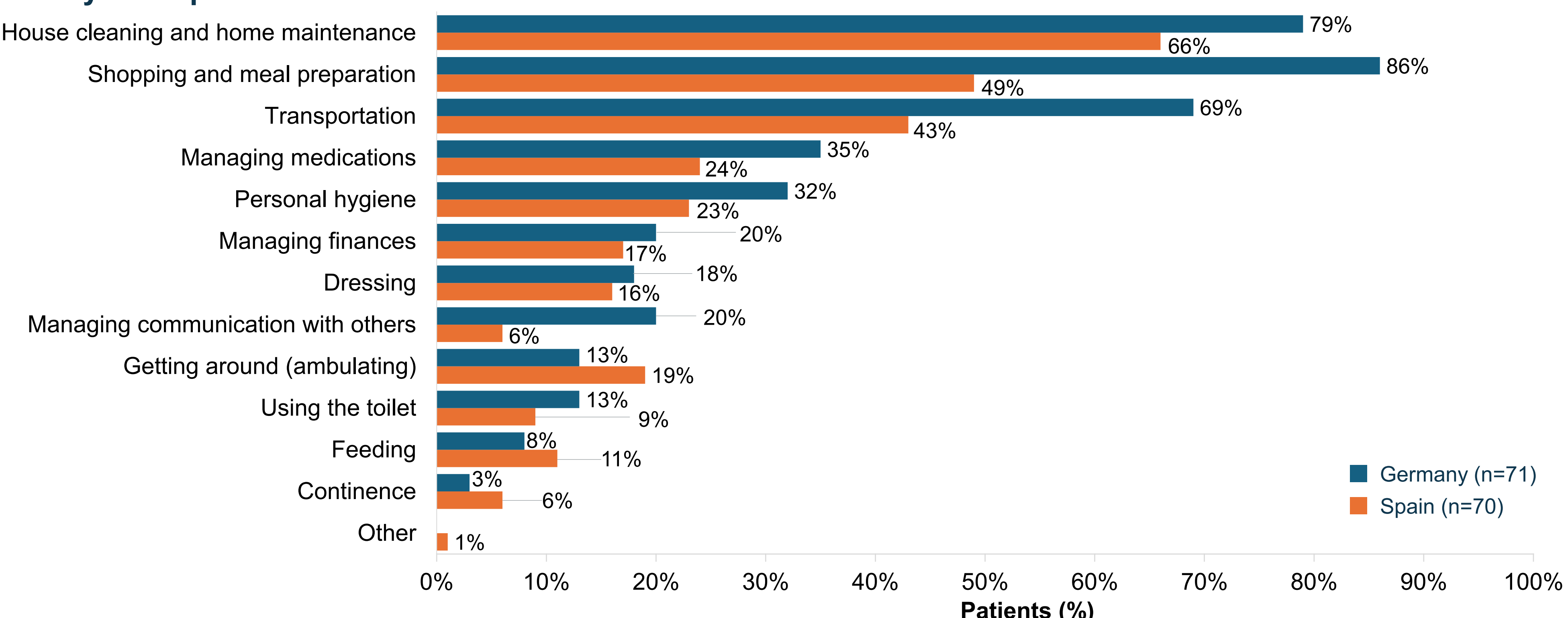
- According to cardiologists, 159/227 (70%) patients required support from a caregiver (Germany: 80/117 [68%]; Spain: 79/110 [72%]) (Figure 1). Caregiving was most often performed by a partner/spouse, followed by adult children and professional caregivers.
- Information on caregiving tasks was available for 71/80 (89%) patients in Germany and 70/79 (89%) patients in Spain (Figure 2). Common caregiving tasks included house cleaning (Germany: 79%; Spain: 66%), shopping/meal preparation (Germany: 86%; Spain: 66%), and transportation (Germany: 69%; Spain: 43%).

Figure 1. Cardiologist-reported relationships of caregivers to patients[†]



[†]Patients for whom cardiologists reported data in the PRF.

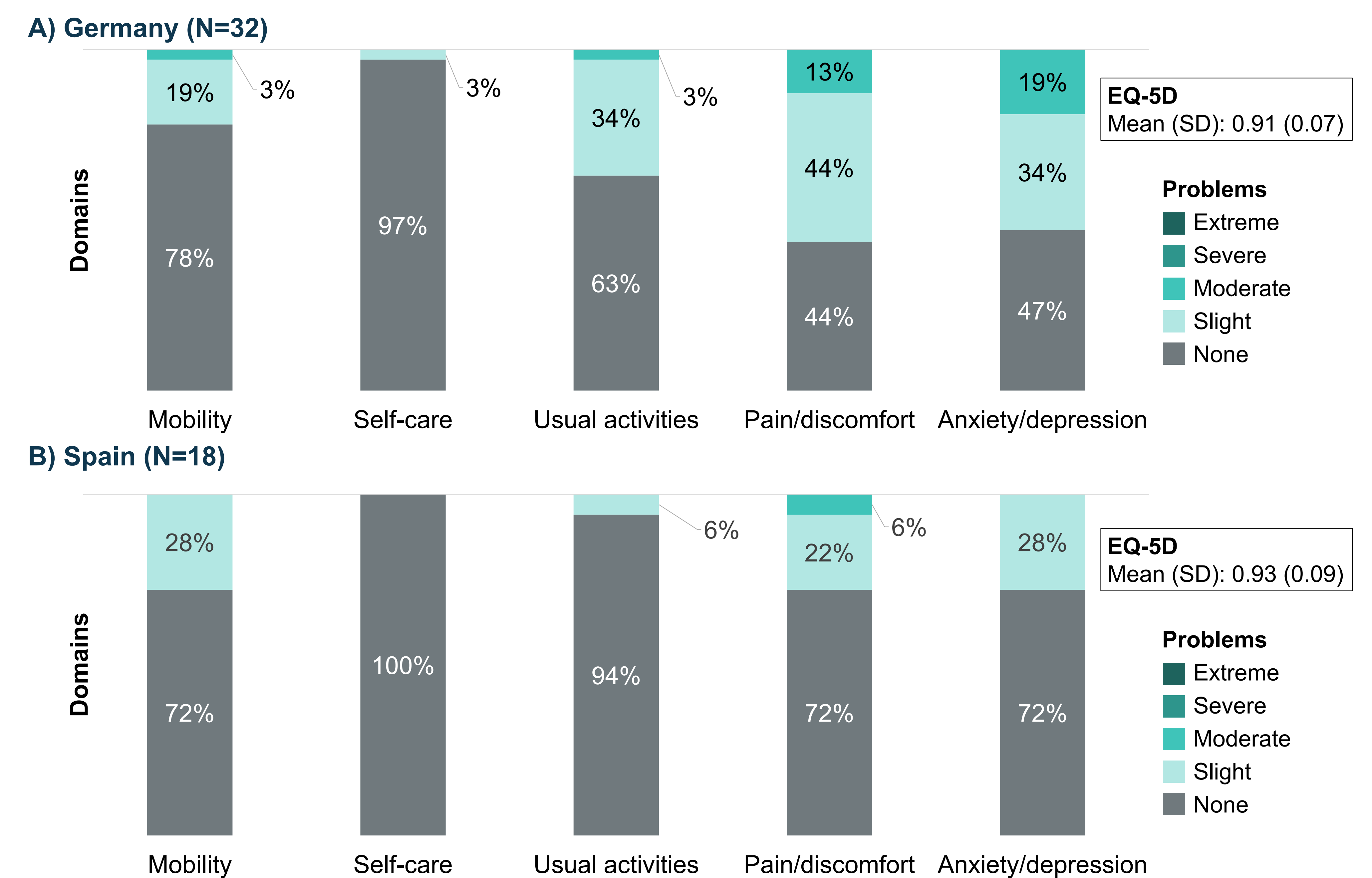
Figure 2. Cardiologist-reported activities of daily living for which patients require help with from a caregiver in Germany and Spain



Caregiver-reported roles and burden

- Caregivers reported spending a mean (SD) of 36 (36) hours per week on caregiving responsibilities (Germany: 31 [18]; Spain: 46 [58]).
- Caregivers had a high health state, with a mean EQ-5D index score (SD) of 0.91 (0.07) in Germany and 0.93 (0.09) in Spain (0 = death; 1 = perfect health^{4,5}). Conversely, caregivers had a mean self-reported EQ-VAS score (SD) of 59 (17) in Germany and 84 (10) in Spain; the EQ-VAS score represents a global health state, scored from 0 (worst) to 100 (best).⁶
- Across the EQ-5D dimensions, caregivers in Germany reported the highest burden in association with pain/discomfort and anxiety/depression, while those in Spain reported the highest burden in association with mobility, pain/discomfort, and anxiety/depression (Figure 3).

Figure 3. Caregiver self-reported EQ-5D[†]



[†]For the EQ-5D, respondents rated each of the five domains (mobility, self-care, usual activities, pain/discomfort, and anxiety/depression) on a five-point Likert scale. A country-specific tariff was applied to their scores to produce an index score ranging between 0 (death) and 1 (perfect health). EQ-5D, EuroQol 5-dimension; SD, standard deviation.



CONCLUSIONS

- In ATTR-CM, caregiving is largely performed by partners/spouses, who spend a substantial amount of time per week supporting patients with household tasks, shopping, meal preparation, and transportation.
- Despite similar health states across countries, caregivers in Germany reported lower overall health levels (on the day of survey) compared with caregivers in Spain, which may reflect cultural differences between countries and the impact of other lifestyle factors on the perceived health status of caregivers.

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