

Need for Caregiver Support for People Living With Hereditary Angioedema in European Countries

Andrea Zanichelli^{1,2}, Laurence Bouillet³, Teresa Caballero⁴, Markus Magerl^{5,6}, Patrick F.K. Yong⁷, Kieran Wynne-Cattanach⁸, Joan Mendivil⁹

¹Università degli Studi di Milano, Dipartimento di Scienze Biomediche per la Salute, Milan, Italy; ²I.R.C.C.S., Policlinico San Donato, Centro Angioedema, UO Medicina, Milan, Italy; ³CHU Grenoble Alpes, Service de Medecine Interne, Centre de reference des Angioedemes, Grenoble, France; ⁴Hospital Universitario La Paz, Servicio de Alergología, Madrid, Spain; ⁵Institute of Allergy, Charité – Universitätsmedizin Berlin, Corporate Member of Freie Universität Berlin and Humboldt-Universität zu Berlin, Berlin, Germany; ⁶Fraunhofer Institute for Translational Medicine and Pharmacology ITMP, Immunology and Allergy, Berlin, Germany; ⁷Frimley Health NHS Foundation Trust, Frimley, Surrey, UK; ⁸Adelphi Real World, Bollington, UK; ⁹Pharvaris GmbH, Zug, Switzerland

Rationale

- Hereditary angioedema (HAE) is a rare genetic condition characterized by painful, often debilitating swelling attacks that can affect multiple locations in the body.^{1,2}
- The need for caregiver support among people with HAE has not been extensively studied in the literature and the requirements for such care are not well understood.
- This analysis aims to examine caregiver support requirements among people living with HAE in some European countries, as well as the impact of their condition on their health-related quality of life (HRQoL) and ability to work.

Methods

- Data were collected through the Adelphi HAE Disease Specific Programme™ (DSP™)* conducted between January 2023–January 2024 in France, Germany, Italy, Spain, and the UK.
- DSPs are real-world, cross-sectional surveys with retrospective data collection.³ A geographically representative sample of physicians were recruited to participate in the DSP.
- Recruited HAE-treating physicians utilized medical charts (from their next ≤10 consecutive consulting patients) and their diagnostic and clinical judgment to provide data on patient demographics and need for caregivers.
- Patients and their caregivers were recruited via the patient's physician and were eligible for inclusion if the patient had a physician-confirmed diagnosis of HAE and both provided informed consent.
- Patients with HAE and caregivers voluntarily reported impact on their work activity (patients only) and HRQoL using self-report forms:
 - Work Productivity and Activity Impairment Questionnaire - Specific Health Problem (WPAI:SHP)⁴: higher scores indicate higher percent work impairment.
 - EQ-5D-Visual Analogue Scale Questionnaire⁵: records general health and functionality calibrated from "worst health you can imagine" (0) to "best health you can imagine" (100).
 - EQ-5D-5L Questionnaire⁶: measures severity of problems across mobility, self-care, usual activities, pain/discomfort, and anxiety/depression (0 bad health–1 good health, relative to the Italy Tariff). The Italy Tariff is a set of values representative of the general adult population in Italy.⁷
- Institutional review board approval was obtained. Descriptive statistics were reported.

Results

- In this analysis, 119 physicians reported data for 593 adult patients with HAE (53% female; mean ± SD age [years], 35.5 ± 14.0) (Table 1).
- Of the 334 (56%) patients currently receiving long-term prophylactic treatment (LTP), 187 (56%) were only using injectable LTP and 135 (40%) only oral LTP. Caregiver support use was reported for 108 patients (18%), 55 of which were receiving only injectable (68%) or oral (28%) LTP (Table 1).

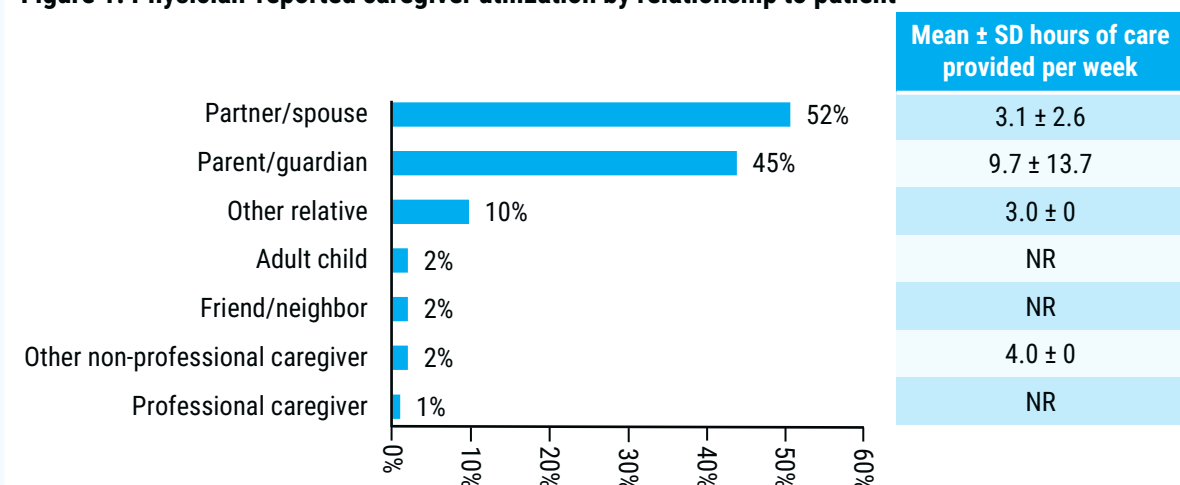
Table 1. Physician-reported patient demographics and baseline characteristics

	Patients without caregiver support (n=485)	Patients with caregiver support (n=108)
Age (years), mean ± SD [range]	36.4 ± 13.8 [18–82]	31.1 ± 14.1 [18–79]
Female, n (%)	255 (53)	58 (54)
Time (years) since diagnosis, mean ± SD [range]	8.1 ± 8.2 [0–47.5] (n=455)	7.9 ± 7.7 [0–49.4] (n=104)
HAE type, ^a n (%)	(n=473)	(n=108)
Type 1	359 (76)	92 (85)
Type 2	91 (19)	9 (8)
HAE with normal C1-INH	23 (5)	7 (6)
Current HAE treatment, n (%)		
Prescribed LTP and ODT	188 (39)	36 (33)
Prescribed LTP only	89 (18)	21 (19)
Prescribed ODT only	189 (39)	47 (44)
Not currently prescribed any treatment	19 (4)	4 (4)
LTP by route of administration, ^b n (%)	(n=267)	(n=55)
Injectable LTP	148 (53)	39 (68)
Oral LTP	119 (43)	16 (28)
Number of HAE attacks in 12 months prior to data collection, mean ± SD [range]	2.1 ± 3.2 [0–30]	3.5 ± 4.4 [0–26]

C1-INH, C1-inhibitor; HAE, hereditary angioedema; LTP, long-term prophylactic treatment; ODT, on-demand treatment; SD, standard deviation. ^aUnknown HAE type excluded from base. ^bPatients on multiple LTP or LTP plus other treatment excluded from base.

- For the 108 patients with caregiver support, assistance was most frequently provided by their partner/spouse or parent/guardian (Figure 1).
- The mean ± SD time that patients received caregiver support per week was 6.6 ± 9.7 hours (Figure 1).

Figure 1. Physician-reported caregiver utilization by relationship to patient^a

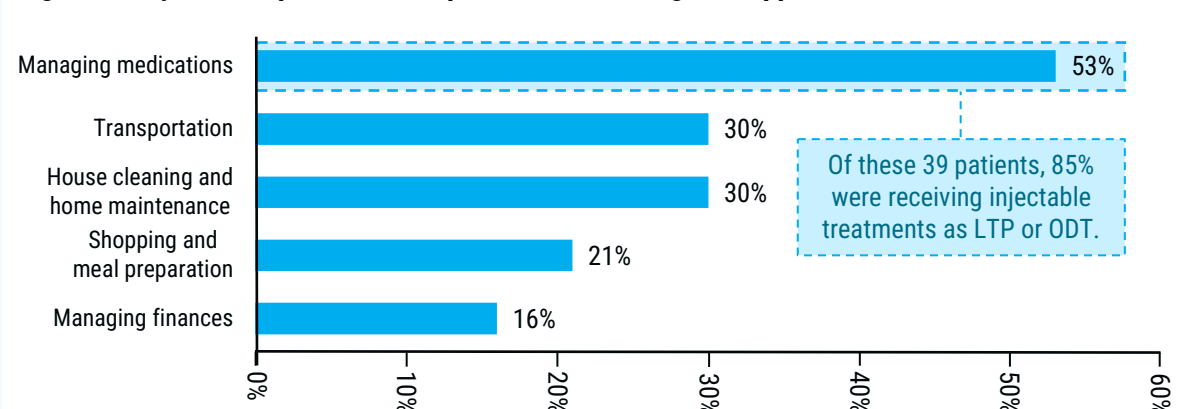


NR, not recorded; SD, standard deviation. ^aRespondents could select more than one category.

Results (continued)

- The activity of daily living (ADL) for which patients most required support was managing medications (53%), followed by transportation (30%), and house cleaning/home maintenance (30%) (Figure 2).

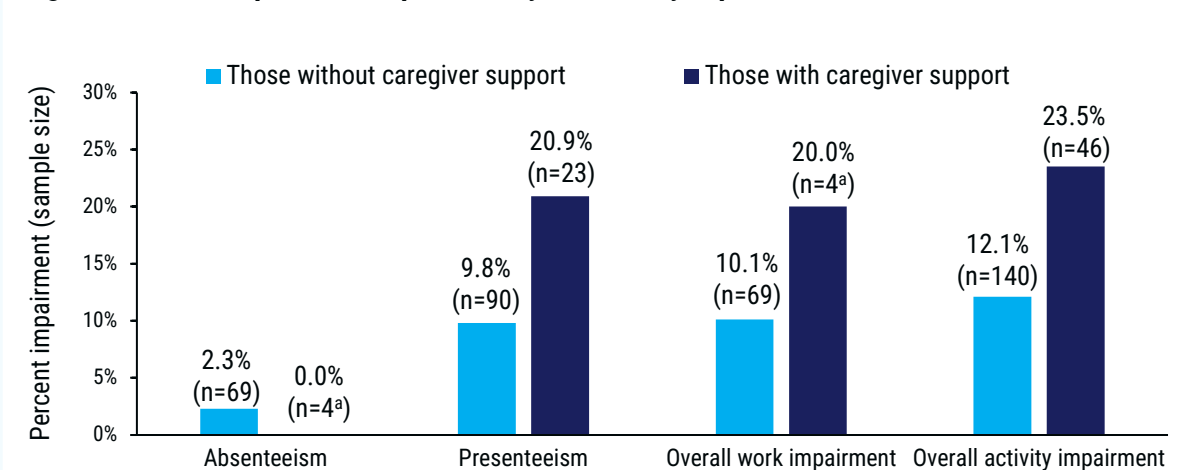
Figure 2. Physician-reported ADL requirements for caregiver support^a



ADL, activity of daily living; LTP, long-term prophylactic treatment; ODT, on-demand treatment. ^an=73 physician-reported patient ADL assessments.

- Patient-reported data (n=187) showed that overall work impairment was higher in patients with caregiver support (mean percent score: 20.0%) vs those with no additional caregiver support (10.1%) (Figure 3).

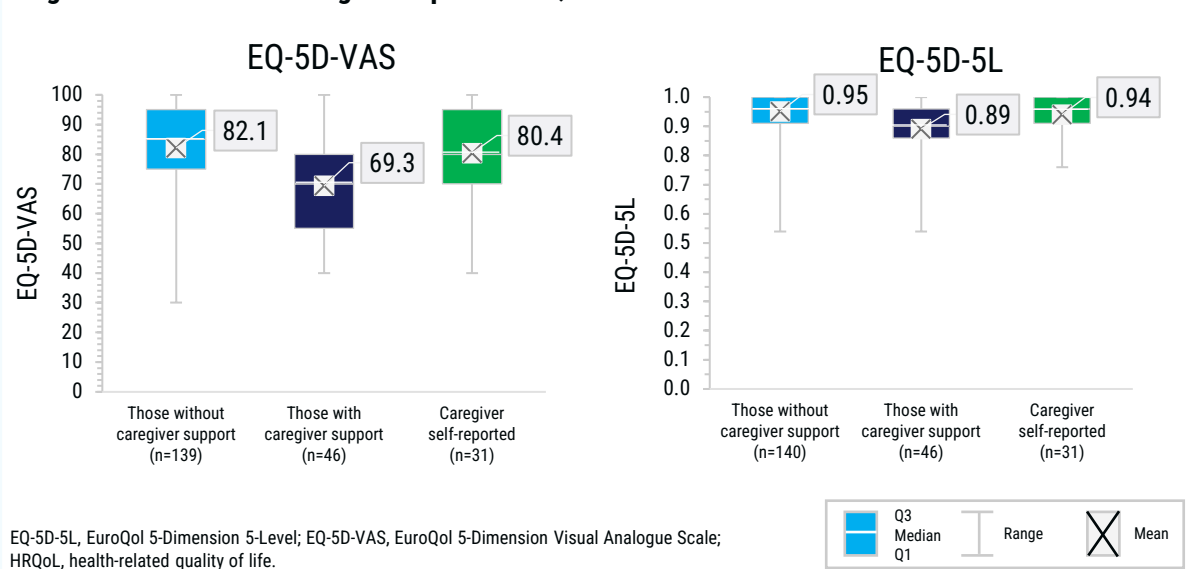
Figure 3. Patient-reported work productivity and activity impairment



HAE, hereditary angioedema. Absenteeism was defined as percent work time missed due to HAE. Presenteeism was defined as percent impairment while working due to HAE. ^aLow base number.

- EQ-5D-VAS and EQ-5D-5L assessments yielded worse mean scores in patients with caregiver support (69.3 and 0.89, respectively) vs patients without caregiver support (82.1 and 0.95, respectively) (Figure 4).
- Caregivers (n=31) reported mean EQ-5D-VAS and EQ-5D-5L scores of 80.4 and 0.94, respectively (Figure 4).

Figure 4. Patient- and caregiver-reported HRQoL



EQ-5D-5L, EuroQol 5-Dimension 5-Level; EQ-5D-VAS, EuroQol 5-Dimension Visual Analogue Scale; HRQoL, health-related quality of life.

Conclusions

- In this study, patients with HAE who reported a greater need for caregiver support also experienced reduced health-related quality of life and reduced work productivity.
- Medication management was reported to be a major factor in the need for caregiver support for people living with HAE in some European countries.

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