

# Understanding the reasons not to treat all HAE attacks and satisfaction for on-demand treatment: physician- and patient-reported data

Mendivil J,<sup>1</sup> Anderson J,<sup>2</sup> Busse P,<sup>3</sup> Lumry W,<sup>4</sup> Riedl M,<sup>5</sup> Earl L<sup>6</sup>

<sup>1</sup>Pharvaris GmbH, Zug, Switzerland; <sup>2</sup>AllerVie Health, Birmingham (AL), United States; <sup>3</sup>Mount Sinai Hospital, Department of Medicine, Allergy & Immunology, New York (NY), United States; <sup>4</sup>Allergy & Asthma Specialists, Dallas (TX), United States; <sup>5</sup>University of California, San Diego, Division of Rheumatology, Allergy & Immunology, La Jolla (CA), United States; <sup>6</sup>Adelphi Real World, Bollington, United Kingdom



## Introduction

- Hereditary angioedema (HAE) is a rare, genetic condition characterized by often painful and debilitating swelling attacks that can affect multiple locations on the body.<sup>1,2</sup>
- Acute treatment of HAE attacks is important to limit the morbidity and mortality of the disease.<sup>3</sup>
- Current HAE clinical guidelines recommend that all patients with HAE should have access to on-demand treatment (ODT) for acute attacks.<sup>3</sup>
- The notion that patients do not treat all HAE attacks is well known by HAE experts but has not been thoroughly documented in the literature. Moreover, reasons behind decisions not to treat HAE attacks remain marginally studied.
- The objective of this analysis was to understand the characteristics of HAE attacks that are not treated and describe physician and patient satisfaction with current ODT used to treat acute attacks.

## Methods

- Data were drawn from the Adelphi HAE Wave II Disease Specific Programme (DSP)<sup>™</sup>, a real-world, cross-sectional survey of patients with HAE and their treating physicians in the United States (data collected between January-September 2023).
- Physicians were eligible for inclusion if they made treatment decisions and managed ≥2 HAE patients in a typical month.
- Physicians provided data from existing patient clinical records and their own clinical judgement/diagnostic skills to report demographics, recent attack history, current prescribed ODT, satisfaction with ODT, use of ODT to treat most recent HAE attack, and reasons for not treating the attack if ODT was not used.
- Patients were recruited via their physician and were eligible for inclusion if they had a physician-confirmed diagnosis of HAE and provided informed consent.
- Patients voluntarily recorded data via self-report forms which included information about their recent attack history, satisfaction with their current ODT, use of ODT to treat their most recent attack, and reasons for not treating their most recent attack if applicable.
- Institutional review board approval was obtained. Descriptive statistics were reported.

## Results

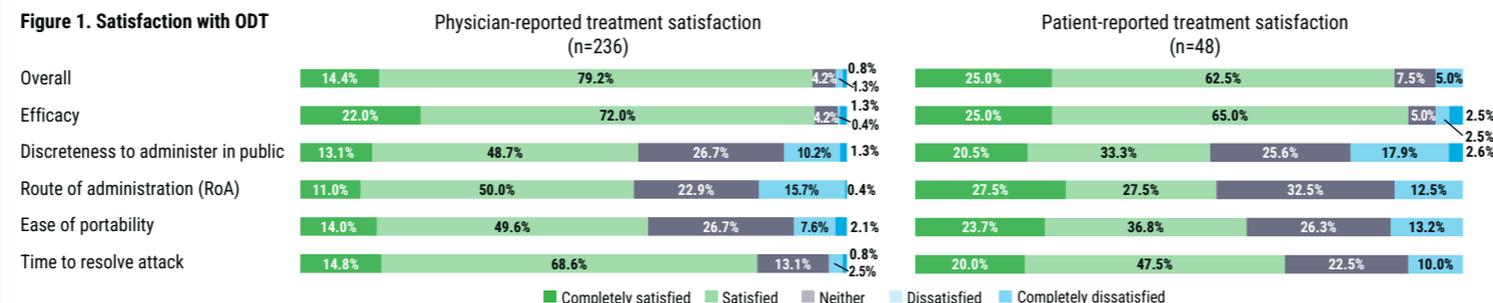
- 73 physicians reported data for 310 patients with HAE. Of these patients, 58 provided self-reported data (Table 1).
- 76% patients were receiving ODT at data collection on average for 3.1 years (Table 2).

**Table 1. Patient demographics and baseline characteristics**

	Physician-reported (n=310)	Patient-reported (n=58)
Age (years), mean ± SD	36.3 ± 14.0	37.5 ± 13.2
Female, n (%)	167 (53.9)	30 (51.7)
Patients in employment or education, n (%)	275 (89.3)	45 (77.6)
Number of comorbidities, mean ± SD	0.9 ± 1.0	1.0 ± 1.0
Years since diagnosis, mean ± SD	7.1 ± 9.0 [n=271]	8.6 ± 11.3 [n=53]
HAE type, n (%)	n=298	n=56
HAE-1	220 (73.8)	37 (66.1)
HAE-2	69 (23.2)	18 (32.1)
HAE-nC1-INH	9 (3.0)	1 (1.8)
Receiving long-term prophylaxis treatment, n (%)	223 (71.9)	47 (81.0)
Receiving on-demand treatment, n (%)	236 (76.1)	43 (74.1)
Number of HAE attacks in the 12 months prior to data collection, mean ± SD	1.7 ± 2.0	2.2 ± 2.6

- Physicians and patients reported not to be satisfied/completely satisfied with ODT in terms of discreteness to administer (38.2% and 46.2%), route of administration (RoA) (39.0% and 45.0%), ease of portability (36.4% and 39.5%), and time to resolve attacks (16.6% and 32.5%) (Figure 1).
- 75.0% of patients treated their most recent attack, waiting on average 56.9 minutes to administer ODT. On average patients reported to wait 145.4 minutes after administering their ODT for their attack related symptoms to start to improve (Table 3).

**Figure 1. Satisfaction with ODT**



**Table 2. Currently prescribed ODT**

	Physician-reported (n=236)	Patient-reported (n=43)
Icatibant, n (%)	151 (64.0)	30 (69.8)
pdC1-INH, n (%)	40 (16.9)	5 (11.6)
rhC1-INH, n (%)	31 (13.1)	5 (11.6)
Ecallantide, n (%)	14 (5.9)	3 (7.0)
Other, n (%)	1 (0.4)*	0 (0.0)
Time receiving current ODT (years), mean ± SD	3.1 ± 3.1 [n=219]	3.2 ± 3.2

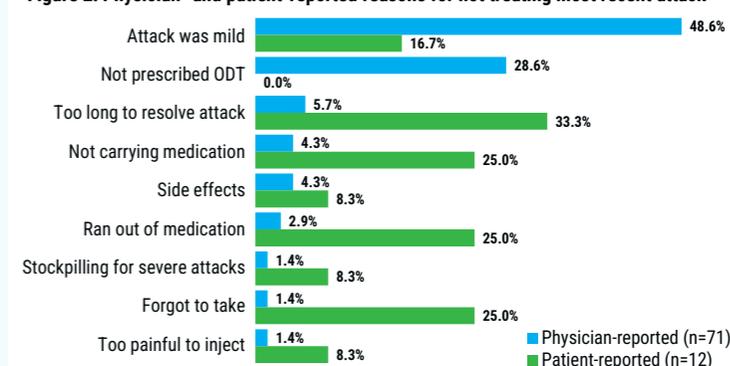
\*Other treatments listed for n=1 patient; steroids, antihistamine, epinephrine.

**Table 3. Treatment of most recent HAE attack**

	Physician-reported (n=294)	Patient-reported (n=58)
Patients that treated their most recent attack, n (%)	224 (76.2)	42 (75.0) [n=56]
Time waited before administering ODT (minutes), mean ± SD	-	56.9 ± 223.3 [n=44]
Time to symptom improvement (minutes), mean ± SD	-	145.4 ± 486.4 [n=42]
ODT used to treat the attack	n=224	n=58
Icatibant, n (%)	133 (59.4)	30 (51.7)
pdC1-INH, n (%)	48 (21.4)	7 (12.1)
rhC1-INH, n (%)	25 (11.2)	3 (5.2)
Ecallantide, n (%)	12 (5.4)	2 (3.4)
Other, n (%)	7 (3.1)	2 (3.4)

- Physician-reported reasons for patients not treating their most recent attack were due to the attack being mild (48.6%) or that the patient was not prescribed ODT (28.6%) (Figure 2).
- Patient-reported reasons for not treating their most recent attack included medication taking too long to resolve attack (33.3%), not carrying medication, running out of medication, or forgetting to take medication (25.0%) (Figure 2).

**Figure 2: Physician- and patient-reported reasons for not treating most recent attack**



## Conclusions

- Patients reported lower satisfaction than physicians with their current ODT in terms of the RoA, discreteness to administer in public, time to resolve attacks, and the ease of portability.
- Three-quarters treated their most recent attack; however, on average, patients waited approximately one hour before administering ODT.
- Patients most frequently reported not treating attacks due to ODT taking too long to resolve the attack.
- These data highlight a lack of satisfaction with current ODT regarding RoA and the portability of current devices. Newer therapies with differential modes of administration and faster onset of action may encourage more consistent and timely treatment of HAE attacks and improved treatment satisfaction.

## References

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