In Their Own Words, Patient Perspectives on Time to Feeling in Control of an HAE Attack

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Background

- Hereditary angioedema (HAE) is characterized by painful, debilitating attacks of tissue swelling in various locations
- WAO/EAACI 2021 updated guidelines recommend:
 - The goals of treatment are to achieve total control of disease and to normalize patients' lives
 - All HAE patients should¹
 - Consider treating all attacks as early as possible
 - Have access to sufficient medication to treat two attacks
 - Carry on-demand treatment at all times, regardless of prophylactic therapy

Objective

Our aim was to examine patient perspectives on what it means to feel in control of their attacks after on-demand treatment

Methods

- The US Hereditary Angioedema Association (HAEA) recruited people living with Type I or II HAE to complete an online survey
 - Recruitment was stratified to include 50% of patients taking on-demand therapy only and 50% receiving long-term prophylaxis + on-demand therapy
- The survey was self-reported and took respondents approximately 20 minutes to complete
- The survey was completed by 107 individuals between September 6 and October 19, 2022; the response rate was 69% (107/155)
- Patients were asked:
 - Question 1: "Why is it important to you to recover quickly from an HAE attack?"
 - Question 2: "How long does it usually take to feel in control of your attack after on-demand treatment (in hours)?"
- Question 3: "How do you know you are in control of your attack after ondemand treatment?"
- Analysis was performed using descriptive statistics

Results

Table 1. Respondent characteristics

Characteristic	Total (N=107)
Age, mean (range), years	41 (16-83)
Gender, n (%) Female Male	86 (80.4) 21 (19.6)
Type of therapy, n (%) On-demand only Prophylaxis and on-demand	53 (49.5) 54 (50.5)
On-demand treatments used, n (%) Icatibant C1 esterase inhibitor (recombinant) C1 esterase inhibitor (plasma-derived) Ecallantide	84 (78.5) 13 (12.1) 9 (8.4) 1 (0.9)
Prophylactic treatments used, n (%) of those using prophylaxis (n=54) Lanadelumab Berotralstat C1 esterase inhibitor (subcutaneous) Androgens/steroids C1 esterase inhibitor (intravenous)	31 (57.4) 7 (13.0) 7 (13.0) 5 (9.3) 4 (7.4)

Figure 1. Selected responses to "Why is it important to you to recover quickly from an HAE attack?"



Nearly all respondents (97%) reported that recovering quickly from an HAE attack was important

Figure 2. Mean time to feel in control of attacks after on-demand treatment

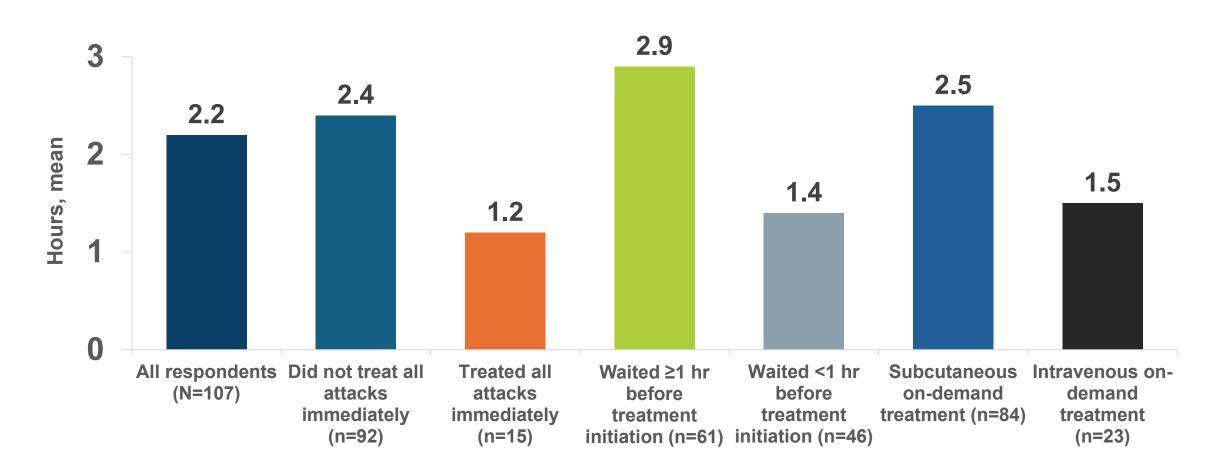


Figure 3. Selected responses to "How do you know you are in control of your attack after on-demand treatment?"



Conclusions

- Results from the survey show that early on-demand treatment initiation is associated with faster time to feeling in control of HAE attacks
- These findings underscore the importance of patient education on early treatment initiation to manage HAE attacks effectively
- Patients describe feeling in control of their attacks in unique ways, highlighting the need for individualized treatment plans based on patient's treatment goals

Reference

1.Maurer M., et al. The international WAO/EAACI guideline for the management of hereditary angioedema - The 2021 revision and update. *World Allergy Organ J.* 2022;15(3):100627.

Disclosures

This study was sponsored by KalVista Pharmaceuticals. All authors met the ICMJE authorship criteria and had full access to relevant data. The authors had full editorial control of the data presented and provided final approval of all content. Neither honoraria nor payments were made for authorship.

DJ - consultant and speaker for KalVista, Takeda, Pharming, CSL, and Genentech, and is a consultant for Pharvaris; AV - received honoraria for educational lectures, consultancy,

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Presented at:

14th C1 Inhibitor Deficiency and Angioedema Workshop – May 29 - June 1, 2025, Budapest, Hungary

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