Delayed On-demand Treatment of Hereditary Angioedema Attacks: Patient Perceptions and Associated Barriers

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Background

- Hereditary angioedema (HAE) is characterized by unpredictable swelling attacks affecting cutaneous and submucosal tissues, which are typically painful, debilitating, and potentially fatal
- WAO/EAACI 2021 updated guidelines recommend the early use of on-demand treatment following attack recognition to reduce morbidity and prevent mortality[1-3]
- Prompt on-demand treatment is essential to limit disease morbidity and mortality
- Despite the recommendation for early treatment, recent research suggests that patients delay on-demand treatment of their HAE attacks[4]

Objective

- We assessed patient perceptions of "early" on-demand use compared to the actual time to treatment administration, in conjunction with barriers contributing to treatment delay

Methods

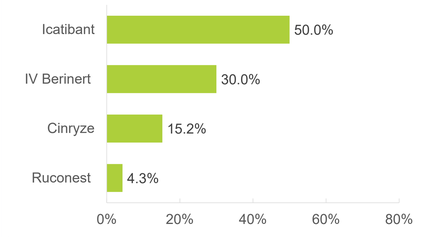
- Participants with Type 1 or 2 HAE were recruited through HAE UK, the patient organization, between April and May 2023
  - Recruitment was stratified to include 50% of participants taking on-demand only and 50% receiving long-term prophylaxis (LTP) + on-demand
- The survey was self-reported, and took respondents approximately 20 minutes to complete
- Study population included participants that were at least 18 years of age, had at least one HAE attack within the three months prior to the survey and had treated that attack with an approved on-demand therapy
- Respondents provided consent for their data to be used anonymously or in aggregate
- Analysis was performed using descriptive statistics

Results

Table 1. Respondent Characteristics

Characteristic	Total (N=46 Adults)	On-demand Only (n=21, 46%)	LTP + On-demand (n=25, 54%)
Current Age (Mean)	44 years	42 years	46 years
Age of Diagnosis (Mean)	17 years	17 years	17 years
Gender			
Male	28%	33%	24%
Female	70%	67%	72%
Prefer not to respond	2%	–	4%
Race / Ethnicity			
White	91%	95%	88%
Black / Black British / Caribbean or African	–	–	–
Asian or Asian British	7%	5%	8%
Other	–	–	–
Prefer not to respond	2%	–	4%
HAE Type			
Type I	100%	100%	100%
Type II	–	–	–
Time Since Last Treated Attack (Mean)	16 days	13 days	18 days

Figure 1. On-Demand Treatment
administered for the last treated attack*



*3 respondents that treated this attack with icatibant, also used a second dose of the same treatment when initial symptoms did not improve after first dose

Figure 2. Long-Term Prophylaxis
at time of last treated attack

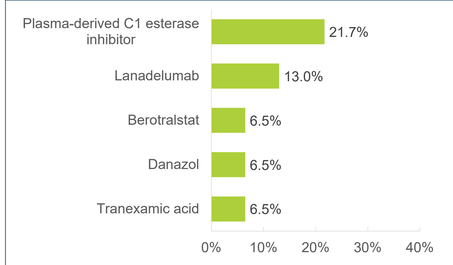
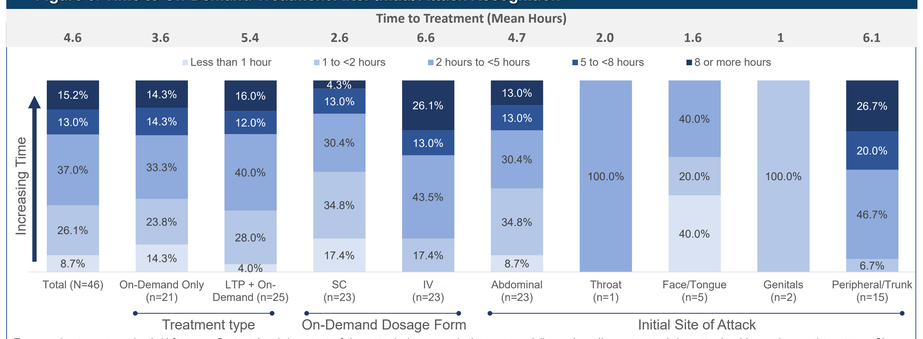


Figure 3. Time to On-Demand Treatment After Initial Attack Recognition



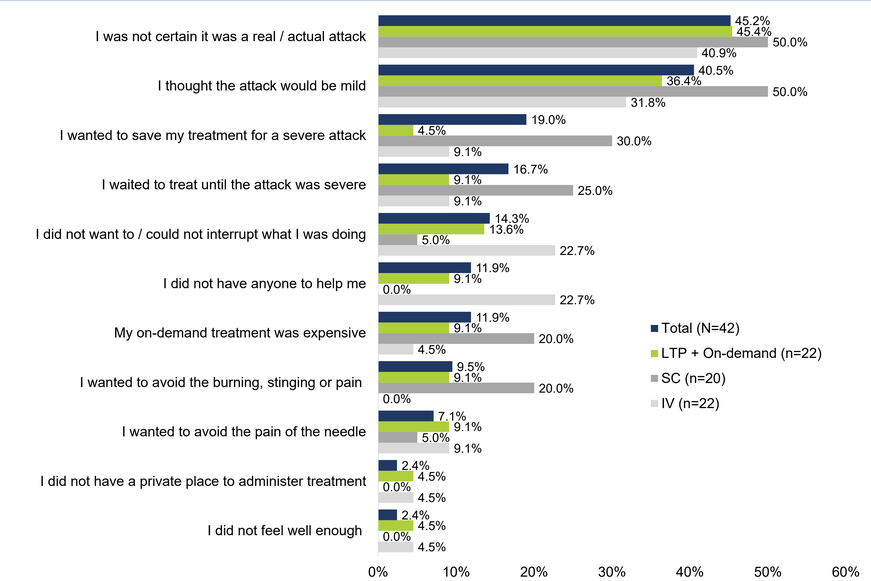
Respondents were asked, 'After you first noticed the start of the attack, how much time passed (hours) until you treated the attack with on-demand treatment?'

Table 2. Patient Perspectives on Time to Treatment of Most Recent Attack

Time to treatment	Total (N=46)	'I treated the attack early' (n=29, 63%)	'I did not treat the attack early' (n=17, 37%)
Less than 1 hour	4 (8.7%)	4 (13.8%)	0 (0%)
1 hour - <2 hours	12 (26.1%)	11 (37.9%)	1 (5.9%)
2 hours - <5 hours	17 (37.0%)	10 (34.5%)	7 (41.2%)
5 hours - <8 hours	6 (13.0%)	3 (10.3%)	3 (17.6%)
8 hours or more	7 (15.2%)	1 (3.4%)	6 (35.3%)
Mean time to treatment	**4.6 hours**	**2.6 hours**	**7.8 hours**

Respondents were asked to select either option to answer the question, 'Which of the following best describes how soon you were able to treat the attack with on-demand treatment?'

Figure 4. Reasons for Delaying On-Demand Treatment (N=42)*



Respondents were asked to rank their top 5 reasons from a list of possible reasons that they would delay administering on-demand treatment *Excludes 4 participants that treated all attacks immediately

Conclusions

- Mean time to on-demand treatment was 4.6 hours; the longest delay occurred when the attack originated in the peripheral/trunk (6.1 hours). Patients receiving IV were more likely to delay treatment (6.6 hours)
- A total of 63% reported their perception of time to treatment as "early" despite only 14% of these patients treating in less than one hour
- Patients taking SC treatment were more likely to delay treatment due to thinking the attack would be mild, wanting to save treatment for a severe attack,, and wanting to avoid burning, stinging or pain
- Patients taking IV treatment were more likely to delay treatment due to not wanting to interrupt what they were doing and not having anyone to help
- Our findings highlight a need to educate patients on treating at the earliest recognition of an attack and proactively address barriers contributing to treatment delays to improve compliance with treatment guidelines and outcomes

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Disclosures

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