

Remaining Burden of Hereditary Angioedema (HAE) Attacks Despite Modern Long-term Prophylaxis

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Background

- HAE is characterized by recurrent and unpredictable episodes of subcutaneous or submucosal swelling which can affect the abdomen, extremities, genitals, face, and larynx and may become life threatening
- Symptoms of an HAE attack can be painful and debilitating, potentially interfering with the ability to conduct daily activities (work, school, social activities)¹
- WAO/EAACI 2022 updated guidelines recommend that all HAE patients:²
 - 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
- Although long-term prophylactic treatment has significantly reduced the frequency of attacks, quality of life has not been fully restored for many people living with HAE³

Rationale

- This survey evaluates the patterns of on-demand treatment and the impacts of HAE attacks and treatment on the day-to-day lives, as reported by people living with HAE receiving prophylactic therapy

Methods

- People living with HAE were recruited by the US Hereditary Angioedema Association (HAEA) to complete an online survey
- 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; response rate 69% (107/155)
- Respondents provided consent for their data to be used anonymously or in aggregate
- Analysis was performed using descriptive statistics

References

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- 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 Apr 7;15(3):100627.
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Results

Table 1. Respondent characteristics

Characteristic	Total (n=107)
Age, mean	41 yrs (Range 16-83 yrs)
Age Category, n (%)	
39yrs and younger	56 (52.3%)
40yrs and older	51 (47.7%)
17yrs and younger	2 (1.9%)
18yrs and older	105 (98.1%)
Gender, n (%)	
Female	86 (80.4%)
Male	21 (19.6%)
Type of Therapy, n (%)	
On-demand only	53 (49.5%)
Prophylaxis with on-demand	54 (50.5%)

Figure 1. Prophylactic treatments used

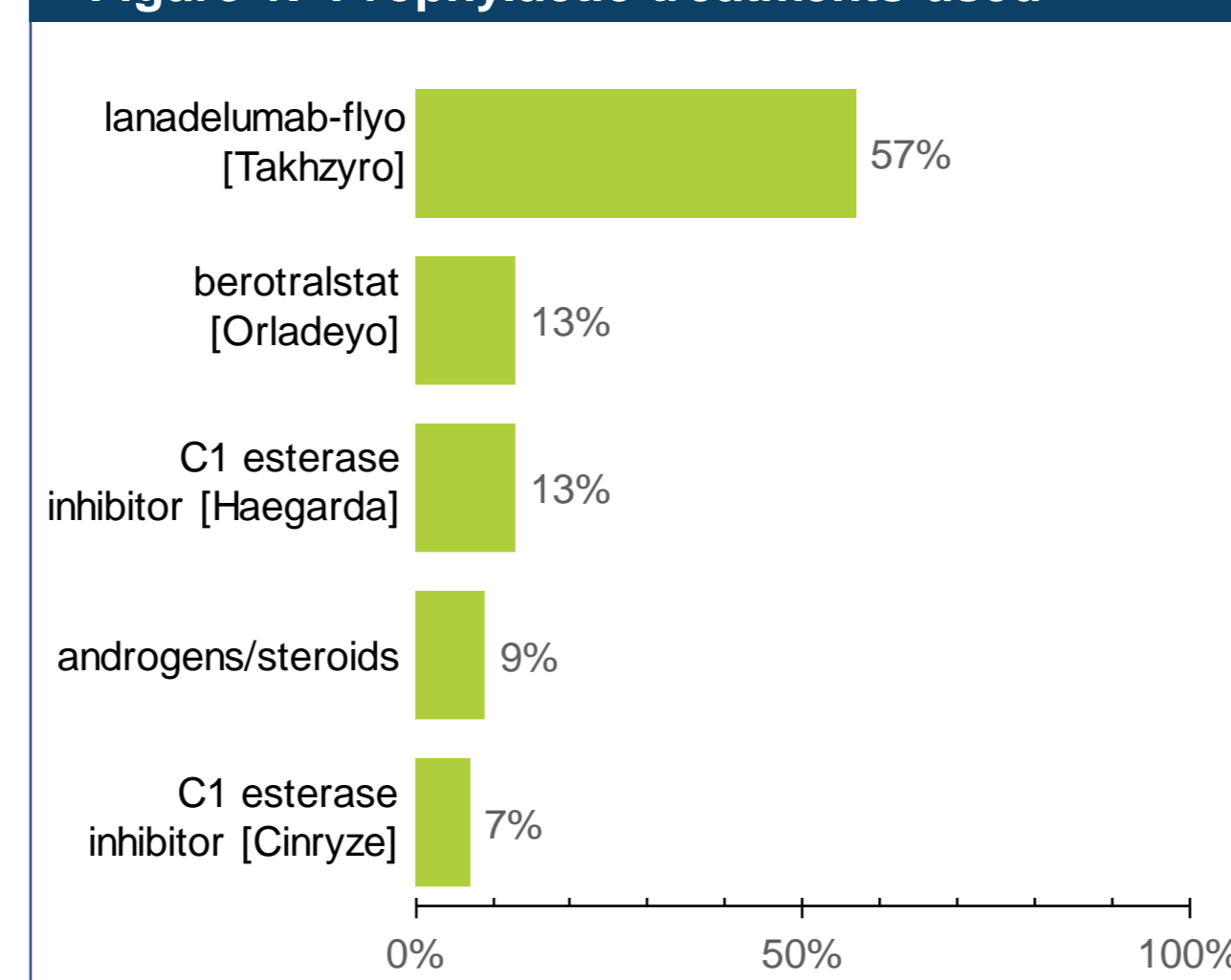


Table 2. Survey statements, questions, and responses

	Prophylaxis + on-demand (n=54)	On-demand only (n=52)	Total (n=107)
Do you treat all HAE attacks?			
% "Yes"	50.0%	63.5%	56.7%*
% "No"	50.0%	36.5%	43.4%*
When an HAE attack occurs, do you feel that you must change your plans for the day? (Of those who do not treat all HAE attacks) (% "Yes")	96.3%	82.3%	88.5%
What are the most common reasons you do not take on-demand treatment with you when away from home?* (Top 5 responses within prophylaxis + on-demand group)	(n=35)	(n=33)	(n=68)
% "I take my prophylactic treatment, so I am confident I won't have an attack"	77.1%	--	39.7%
% "I would rather treat at home"	65.7%	78.8%	72.1%
% "I forget to take it with me"	60.0%	51.5%	55.9%
% "I am afraid I might leave it somewhere"	51.4%	42.4%	47.1%
% "I avoid my triggers"	42.9%	45.5%	44.1%
Percent of patients that reported they do not feel like 100% themselves all of the time because of their HAE (mean %)	96.3%	90.6%	93.5%
Proportion of the time patients reported that they feel less than 100% of themselves, because of their HAE (mean %)	41.3%	30.1%	35.7%

*n=106; **Respondents were provided with a list of responses and instructed to select all that apply.

Table 3. Reported impacts of on-demand HAE attack treatment despite being on prophylaxis

Question: Does your on-demand HAE treatment impact each of the following? (% "Yes")	Prophylaxis + on-demand (n=54)	Total (n=107)
School	37.0%	29.9%
Work (day to day work)	53.7%	57.0%
Work (choice of work)	51.9%	53.3%
Sports (participation in sports)	48.1%	50.5%
Travel (choice of destination)	57.4%	60.7%
Social Activities (participation in social activities)	53.7%	57.0%

Conclusions

- Despite the promise of modern prophylactic treatment to allow people with HAE to live normal lives, considerable burden of HAE on patients' day-to-day life remains
- Half of patients on prophylaxis do not treat all of their HAE attacks with on-demand treatment
- Many patients on prophylaxis do not carry their on-demand treatment with them, feeling confident that if they avoid triggers, their prophylaxis will provide adequate disease control
- Despite being on prophylaxis, on-demand HAE treatment still impacts many aspects of patients' lives, including work, school, travel, sports and social activities

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