Abstract #000522

Understanding the Complex Decision-Making Associated with On-Demand Treatment of Hereditary Angioedema (HAE) Attacks

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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
- 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 use
- Although self-administration of on-demand parenteral treatments has enhanced overall HAE attack management,[3] little is known about decision making as to when and if to administer on-demand treatment

Rationale

- This survey evaluated the key factors that drive on-demand treatment decision-making, as reported by those living with HAE

Methods

- The US Hereditary Angioedema Association (HAEA) recruited people living with HAE to complete an online survey
- The survey was self-reported, and took respondents approximately 20 minutes to complete
- 107 individuals completed the survey between September 6 and October 19, 2022
- Respondents provided consent for their data to be used anonymously or in aggregate
- Analysis was performed using descriptive statistics

Table 1. Respondent characteristics

Characteristic	Total (n=107)
Age, mean (range)	41yrs (16-83)
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%)

Results

Table 2. Survey statements, questions and responses

	Total (n=107)	Prophylaxis + On-demand (n=54)	On-demand Only (n=53)
Is it important to you to recover quickly from an HAE attack? (% "Yes")	**97.2%**	96.3%	98.1%
My level of anxiety decreases once I realize I am recovering from my HAE attack (% "Agree")	**95.3%**	94.4%	96.2%
It takes me longer to recover from an HAE attack when I delay using my on-demand treatment (% "Agree")	**80.4%**	79.6%	81.1%
My HAE attacks are more severe when I delay using my on-demand treatment (% "Agree")	**74.8%**	74.1%	75.5%
Is access to a private area for injecting on-demand treatment a barrier to treating attacks quickly? (% "Yes")	**31.8%**	31.5%	32.1%
What are the most common reasons you do not take on-demand treatment with you when away from home? (Top 4 responses)			
% "I would rather treat at home"	**72.1%**	65.7%	78.8%
% "I forget to take it with me"	**55.9%**	60.0%	51.5%
% "I am afraid I might leave it somewhere"	**47.1%**	51.4%	42.4%
% "I avoid my triggers"	**44.1%**	42.9%	45.5%

Table 3. Reasons for delaying on-demand treatment of an HAE attack

Question: What are the most important reasons you might wait to treat an HAE attack? (Any Rank)	Total (n=107)	Prophylaxis + On-demand (n=54)	On-demand Only (n=53)
The attack is not severe enough to treat	**75.7%**	70.40%	81.10%
I do not have on-demand treatment with me	**45.8%**	48.10%	43.40%
Cost of on-demand treatment	**34.6%**	35.2%	34.0%
I do not have any important activities that will be disrupted by the attack	**32.7%**	29.6%	35.8%
Anxiety associated with refilling my on-demand treatment quickly	**31.8%**	31.5%	32.1%
My on-demand treatment is too painful (injection or burning)	**24.3%**	22.2%	26.4%
I do not have a suitable/private area to administer my on-demand treatment	**23.4%**	20.4%	26.4%
Important activities will be disrupted by treatment	**16.8%**	20.4%	13.2%
I do not have the necessary time required to prepare on-demand treatment	**14.0%**	16.7%	11.3%
I have a fear of needles	**11.2%**	9.3%	13.2%
Other	**7.5%**	9.3%	5.7%
I always immediately treat my HAE attacks	**14.0%**	18.5%	9.4%

Conclusions

- **Survey results highlight the complexity of treatment decision-making for people living with HAE**
- **Virtually all HAE patients surveyed believe it is important to recover quickly from HAE attacks and that level of anxiety decreases once they realize they are recovering from their HAE attack**
- **The majority of patients find that their HAE attacks progress in severity and it takes longer to recover when they delay using their on-demand treatment**
- **Treatment-related limitations, such as fear of needles, painful treatment, time required to prepare treatment and the need for a suitable/private area to administer treatment, can be the cause of on-demand treatment delay**
- **Findings were consistent among those who are on prophylaxis, as well as those who are using on-demand treatment only**

References

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