Burden of Injectable On-Demand Treatment for Hereditary Angioedema Attacks in Children

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Background

- Injectable on-demand treatments for hereditary angioedema (HAE) attacks can be painful and challenging to administer and may be especially burdensome for young children[1]
- We sought to describe the burden of injectable on-demand treatment on young children—relative their last attack—from an online survey of children with HAE and their caregivers

Methods

- Adult caregivers (aged ≥21 years) of children aged 2–11 years with HAE type 1 or type 2 were recruited by the US HAE Association to participate in a 20-minute online quantitative survey
- To be eligible, the caregiver had to provide caregiving and support for the management of their child's HAE attack within the past 6 months
- Anxiety was measured using a Generalized Anxiety – Numeric Rating Scale (GA-NRS) from 0 (not anxious) to 10 (extremely anxious)

Results

- Data were collected between July and December 2025 from 26 caregivers (all parents) of 30 children with HAE in the United States

Table 1. Demographics and characteristics of children with HAE

	N=30 children
Mean age, years (SD)	8.5 (2.2)
Male gender, n (%)	17 (56.7)
Type 1 HAE, n (%)	29 (96.7)
Median number of attacks in the past 12 months (IQR)	4 (2–6)
Median number of treated attacks in the past 12 months (IQR)	2 (0–3)
Treated at least 1 attack at an emergency center in the past 12 months, n (%)	9 (30.0)
Level of anxiety while attack free, n (%)	
Not anxious	12 (40.0)
Mild	7 (23.3)
Moderately	7 (23.3)
Extremely	4 (13.0)
Receiving LTP, n (%)	9 (30.0)

HAE, hereditary angioedema; IQR, interquartile range; SD, standard deviation.

- In the past 12 months, children had a median of 4 attacks (**Table 1**) and a median of 2 attacks were treated with an injectable on-demand treatment

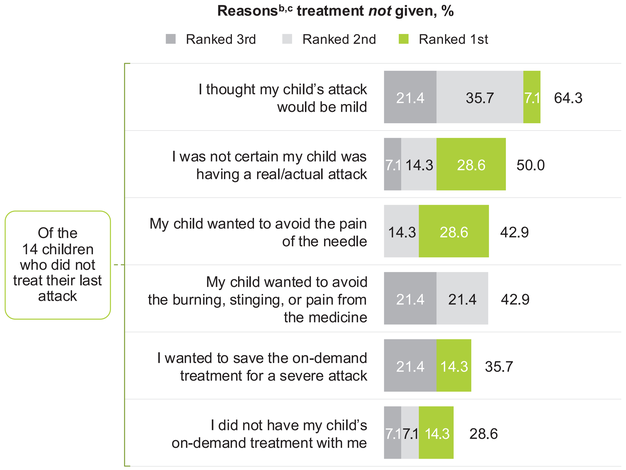
Results

Table 2. Characteristics of child's last attack

Characteristic	N=30
Initial site of attack, n (%)	
Abdomen/stomach	14 (46.7)
Peripheral/trunk	8 (26.7)
Face	4 (13.3)
Genitals	3 (10.0)
Throat/tongue	1 (3.3)
Attack was treated with on-demand treatment, n (%)	16 (53.3)
Attack duration, days, mean (SD)	1.2 (1.1)
Treated	0.9 (1.0)
Untreated	1.5 (1.1)
Attack was treated in an emergency center,[a] n (%)	5 (31.3)
On-demand treatment taken for attack,[a] n (%)	
C1INH, IV (Berinert)	10 (62.5)
Icatibant, SC	5 (31.3)
C1INH, IV (Cinryze)	1 (6.3)
Total time from start of attack to on-demand treatment,[a] hours, mean (SD)	2.8 (2.6)
Attack severity at time of treatment,[a] n (%)	
Mild	7 (43.8)
Moderate	7 (43.8)
Severe	2 (12.5)

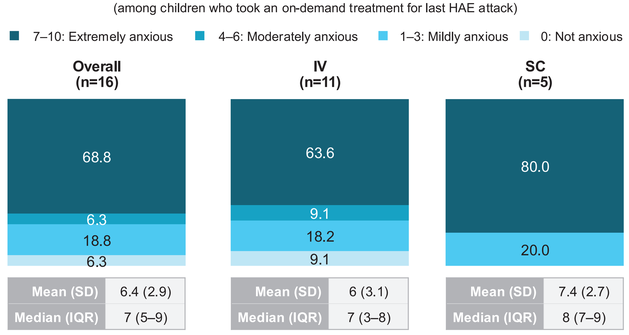
[a]Among those whose child took an on-demand treatment for their last HAE attack; n=16.
C1INH, C1 esterase inhibitor; HAE, hereditary angioedema; IV, intravenous; LTP, long-term prophylaxis; SC, subcutaneous; SD, standard deviation.

Figure 1. Reasons that the child was not treated for their last attack[a]



[a]Percentages in bars may not equal total percentages due to rounding. [b]Only data points totaling ≥10% shown. [c]Caregivers were able to select their top 3 options.

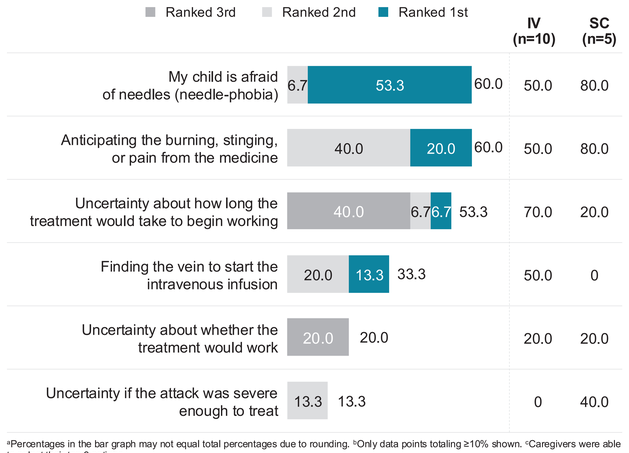
Figure 2. Anxiety of children over taking injectable on-demand treatment[a]



[a]Percentages in bars may not equal 100% due to rounding.
HAE, hereditary angioedema; IQR, interquartile range; IV, intravenous; SC, subcutaneous; SD, standard deviation.

- Among children who were treated for their last attack, most (93.7%) experienced anxiety about taking their injectable on-demand treatment (**Figure 2**)

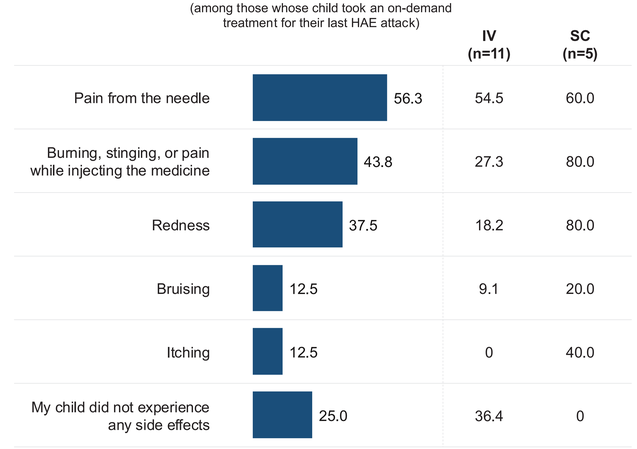
Figure 3. Children's reasons for anxiety regarding taking injectable on-demand treatment[a] (n=15)



[a]Percentages in the bar graph may not equal total percentages due to rounding. [b]Only data points totaling ≥10% shown. [c]Caregivers were able to select their top 3 options.
IV, intravenous; SC, subcutaneous.

- Most (80%) children who received subcutaneously (SC) administered treatment and half (50%) who received intravenously (IV) administered treatment had anxiety due to fear of needles (**Figure 3**)

Figure 4. Side effects of injectable on-demand treatment in children (n=16)



[a]Only data points totaling ≥10% shown.
HAE, hereditary angioedema; IV, intravenous; SC, subcutaneous.

- Overall, 75.0% of children had a side effect from their injectable on-demand treatment (**Figure 4**)
  - All side effects shown were experienced by children who received SC-administered treatment

Conclusions

- **Almost half the children were not treated for their last HAE attack**
- **Among those children who were treated for their last attack, approximately one-third (31.3%) had their attack treated in an emergency center**
- **An FDA-approved treatment (ie, C1INH [Berinert]) was used for 62.5% of last attacks**
- **Nearly all children who received an injectable on-demand treatment were anxious about receiving their treatment, with most experiencing extreme anxiety—including 80.0% of children who received SC treatment**
- **Over half (63.6%) of children who received their on-demand treatment IV and 100% who received their treatment SC reported a side effect from their treatment**

References

1. Christiansen S, et al. *Ann Allergy Asthma Immunol*. 2025;134(5):570–579.e4.

Disclosures

TJC served as a speaker/researcher for Astria, CSL Behring, KalVista Pharmaceuticals, and Takeda; a researcher for ADARx Pharmaceuticals, Argo, BioMarin, Intellia Therapeutics, Ionis, and Pharvaris; speaker for Grifols; consultant for ADARx Pharmaceuticals, Astria, BioCryst, CSL Behring, Intellia Therapeutics, KalVista Pharmaceuticals, Pharvaris, and Takeda; Director of the Angioedema Centers of Reference and Excellence (ACARE) International Hereditary Angioedema Center; and member of the Medical Advisory Board for the United States Hereditary Angioedema Association (HAEA). **RT** has received grants, consulting fees, honoraria, and/or served on advisory boards and/or data safety monitoring boards for AstraZeneca, Astria Therapeutics, BioCryst, CSL Behring, GSK, Ionis Pharmaceuticals, KalVista Pharmaceuticals, Pharming, Pharvaris, Regeneron, Sanofi, and Takeda. **SD** and **JU** have received consulting fees from KalVista Pharmaceuticals. **JM**, **PB**, and **PKA** are salaried employees of KalVista Pharmaceuticals. **HHL** is a speaker for BioCryst, CSL Behring, Pharming, and Takeda, and has received research and consultancy grants from BioCryst,BioMarin, CSL Behring, Ionis, Pharming, Pharvaris, and Takeda.

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