Caregiver Burden Associated with Injectable On-Demand Treatment of Hereditary Angioedema Attacks in Children

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Background

- Pediatric guidelines recommend that all hereditary angioedema (HAE) attacks in pediatric patients be managed using on-demand treatment as early as possible[1]
- Injectable on-demand treatments for HAE attacks can be painful and challenging to administer and may be especially burdensome for young children as well as their caregivers[2]
- The present interim analysis from an online survey of young children with HAE and their caregivers describes the burden of injectable on-demand treatment on caregivers and identifies barriers to treating the attack

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 have provided caregiving and support for the management of their child's HAE attack within the last 6 months
- Anxiety was measured using a Generalized Anxiety – Numeric Rating Scale (GA-NRS) from 0 (not anxious) to 10 (extremely anxious)

Results

Table 1. Caregiver demographics and characteristics

Demographics and characteristics of caregivers	N=26
Mean age, years (SD)	38.8 (6.3)
Gender, n (%)	
Female	24 (92.3)
Male	2 (7.7)
Mean number of children (SD)	2.3 (1.1)
Mean number of children with HAE (SD)	1.4 (0.6)
HAE diagnosis, n (%)	18 (69.2)

HAE, hereditary angioedema; SD, standard deviation.

- Data were collected between July and December 2025 from 26 caregivers (all parents) in the United States, 69.2% of whom also had an HAE diagnosis (**Table 1**)

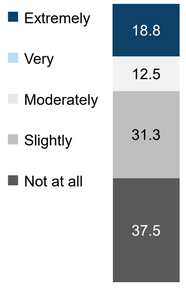
Results

Table 2. Caregiver burden for child's last attack

Caregiver burden	N=30 children
Child's attack started outside their home, n (%)	13 (43.3)
Caregiver not with child when attack occurred, n (%)	11 (36.7)
Child required assistance administering injectable on-demand treatment for their attack, n (%)	11 (68.8)[a]
Child not treated for their attack, n (%)	14 (46.7)
Days of school missed for attack,[b] n (%)	[n=29][c]
0	17 (58.6)
1	7 (24.1)
2	3 (10.3)
3–4	2 (6.9)
Hours of work missed due to attack,[d] median (IQR)	3 (0–14)

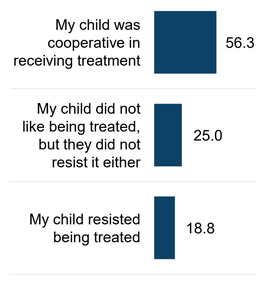
[a]Of children who were treated, n=16 (C1INH, IV [Berinert]: 6/10; icatibant, SC: 4/5; C1INH, IV [Cinryze]: 1/1). [b]Applies to school-age children. [c]One missing. [d]Of those employed (n=25).
IV, intravenous; SC, subcutaneous.

Figure 1. Difficulty in treatment administration (n=16),[a] %



[a]Percentages in bars may not equal 100% due to rounding.

Figure 2. Child's reaction to receiving treatment (n=16),[a] %

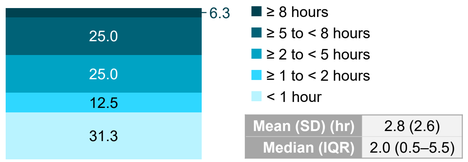


[a]Percentages in bars may not equal 100% due to rounding.

- Of the 16 children who received injectable on-demand treatment for their last attack, 43.8 resisted or did not like being treated (**Figure 1**)
- Overall, 62.5% of children had some level of difficulty with on-demand treatment administration (**Figure 2**)

Figure 3. Time from attack onset to administration of injectable on-demand treatment[a] (n=16)

Time from attack onset to on-demand treatment, %
(Among those whose child took an on-demand treatment for their last attack)



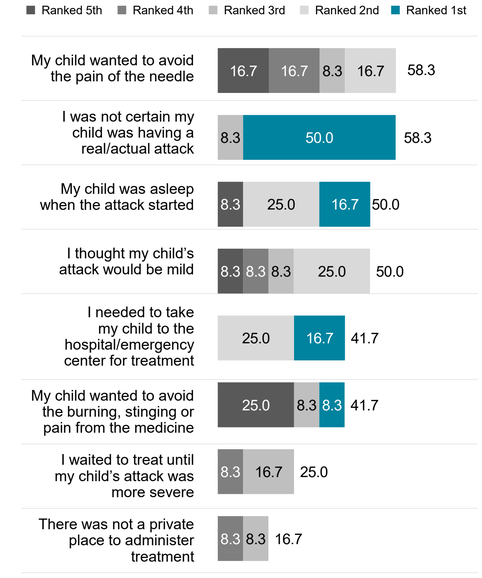
Mean (SD) (hr)	2.8 (2.6)
Median (IQR)	2.0 (0.5–5.5)

[a]Mean time to treatment—defined as the amount of time that passed from the start of the child's attack to when they received their injectable on-demand treatment.
HAE, hereditary angioedema; IQR, interquartile range; SD, standard deviation.

- Time from attack onset to on-demand treatment occurred on average 2.8 hours (**Figure 3**)
- Mean time to prepare and administer treatment was 25.8 (SD 25.8) minutes

Figure 4. Caregiver reasons for delaying injectable on-demand treatment for their child's last attack[a] (n=12)

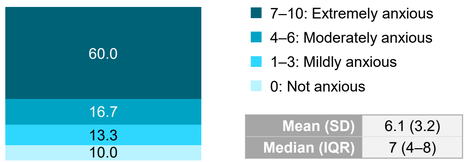
Barriers,[b] %
(Excluding those who treated the attack immediately)



[a]Percentages in bars may not equal 100% due to rounding. [b]Caregivers were able to select their top 5 options.

Figure 5. Level of caregiver anxiety regarding the decision to treat their child's last attack with injectable on-demand treatment (n=30)

Caregiver anxiety level about decision to treat last attack, %

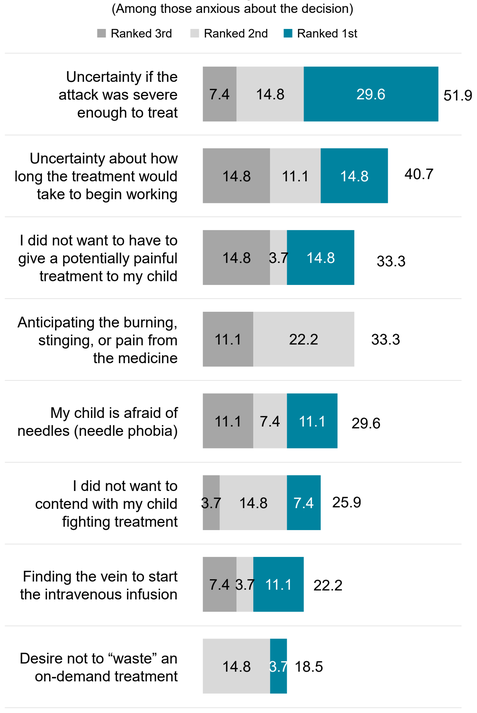


Mean (SD)	6.1 (3.2)
Median (IQR)	7 (4–8)

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

Figure 6. Reasons for caregiver anxiety about the decision to treat their child with injectable on-demand treatment[a] (n=27)

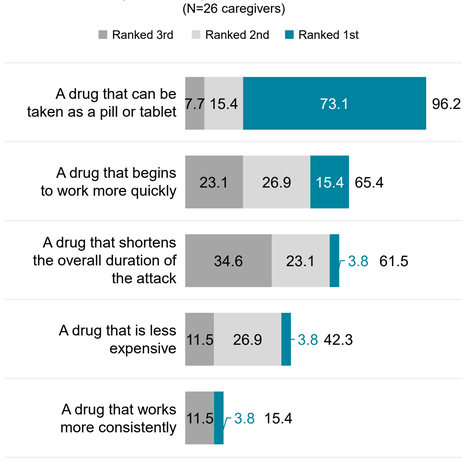
Reasons[b,c] for anxiety to treatment, %
(Among those anxious about the decision)



[a]Percentages in bars may not equal 100% due to rounding. [b]Only datapoints totaling ≥10% shown. [c]Caregivers were able to select their top 3 options.

Figure 7. Caregivers ranking of what they feel would be the most important improvements to injectable on-demand treatment[a] (N=26)

Most important[b] improvements for treatment, %
(N=26 caregivers)



[a]Percentages in bars may not equal 100% due to rounding. [b]Only datapoints totaling ≥10% shown. [c]Caregivers were able to select their top 3 options.

- When parents were asked to rank the most important thing that could make on-demand treatment better for their child, almost all (96.2%) chose oral therapy (**Figure 7**)

Conclusions

- **More than half of parents had difficulty administering injectable on-demand treatment for their child's HAE attack**
- **Over half (60%) of parents were extremely anxious over the decision to treat their child**
- **Top reasons for anxiety were uncertainty whether the attack was severe enough to warrant treatment, uncertainty about how long it would take the treatment to begin working, and not wanting to give a potentially painful treatment to their child**
- **Parents ranked oral therapy as the most important attribute for improving on-demand treatment for their child**

References

1. Farkas H, et al. *Allergy.* 2026 Jan 30. Epub ahead of print.
2. Christiansen S, et al. *Ann Allergy Asthma Immunol.* 2025;134(5):570–579.e4.

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