

# The Hereditary Angioedema (HAE) Attack Journey: A Conceptual Model of Patient Anxiety and On-Demand Treatment Burden During an HAE Attack

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## Background

- People with HAE experience a complex decision-making process during which anxiety can be associated with delays in on-demand treatment of HAE attacks
- The objective of this analysis was to investigate patient anxiety when anticipating on-demand treatment and factors influencing on-demand treatment of HAE attacks

## Methods

- The US Hereditary Angioedema Association (HAEA) recruited people living with HAE to complete an online survey
  - Recruitment was stratified to include 50% of patients taking on-demand therapy only and 50% receiving long-term prophylaxis plus on-demand therapy
- 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 was 69% (107/155)
- Respondents provided consent for their data to be used anonymously or in aggregate
- Analysis was performed using descriptive statistics

## Results

- Respondents included 107 Type I or II HAE patients, 80.4% female, mean age 41 years (**Table 1**)

### Disclosures

This study was sponsored by KalVista Pharmaceuticals. All authors met the ICMJE authorship criteria and had full access to relevant data. The authors had full editorial control of the data presented and provided final approval of all content. Neither honoraria nor payments were made for authorship.

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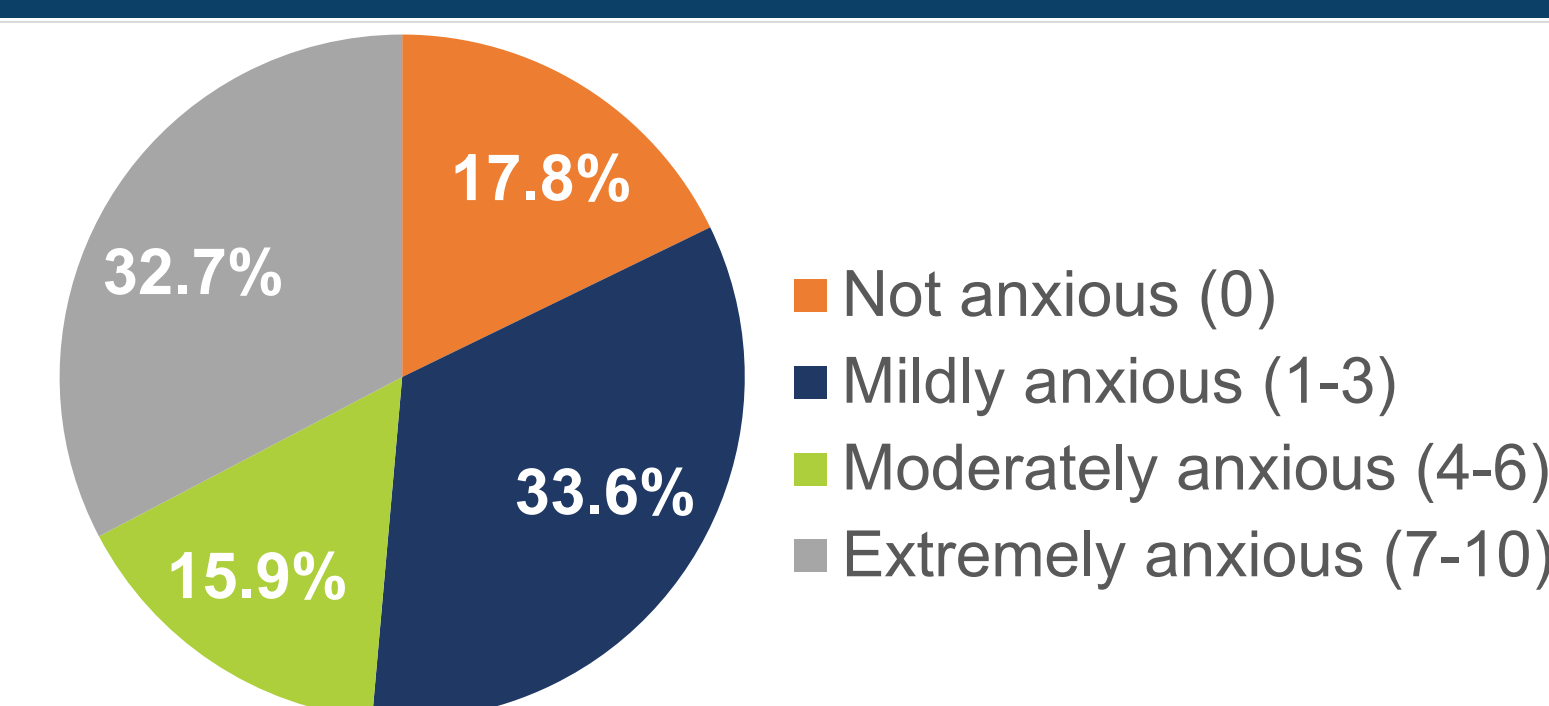
## Results

**Table 1. Respondent characteristics**

Characteristic	Total (N=107)
<b>Age, mean (range), years</b>	41 (16-83)
<b>Gender, n (%)</b>	
Female	86 (80.4)
Male	21 (19.6)
<b>Type of therapy, n (%)</b>	
On-demand only	53 (49.5)
Prophylaxis without-demand	54 (50.5)
<b>On-demand treatments used, n (%)</b>	
Icatibant	84 (78.5)
C1 esterase inhibitor (recombinant)	13 (12.1)
C1 esterase inhibitor (human)	9 (8.4)
Ecallantide	1 (0.9)
<b>Time to administration of on-demand treatment, n (%)</b>	
<1 hour	46 (43.0)
≥1 hour	61 (57.0)
<b>Prophylactic treatments used, n (%) of those using prophylaxis (n=54)</b>	
Lanadelumab	31 (57.4)
Berotrastat	7 (13.0)
C1 esterase inhibitor (subcutaneous)	5 (9.3)
Androgens/steroids	4 (7.4)
C1 esterase inhibitor (intravenous)	4 (7.4)

- Respondents rated their anxiety level on a 0 to 10 scale when anticipating the use of their current on-demand treatment (**Figure 1**)

**Figure 1. Respondents' anxiety level when anticipating the use of their current on-demand treatment**



## Results

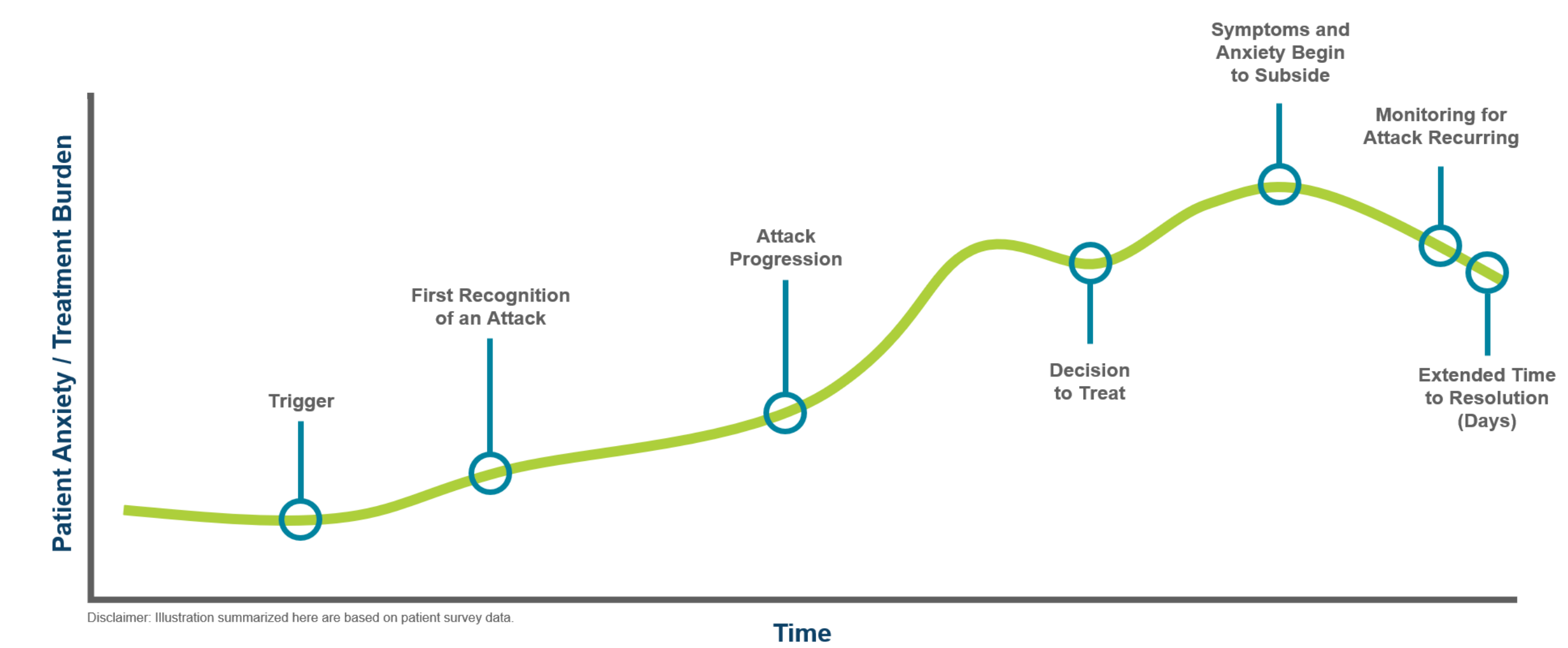
- Respondents reported a mean ( $\pm$ SD) anxiety level of 4.2 ( $\pm$ 3.4) on a 0 to 10 scale when anticipating the use of their current on-demand treatment
- Respondents treated their HAE attack an average of 2.4 hours after recognizing the initial onset of the attack
- Respondents who reported feeling extremely anxious (rating  $\geq$ 7) when anticipating the use of on-demand treatment reported delaying treatment a mean time of 4.3 hours compared with 1.7 hours for those who were moderately anxious (rating 4–6)
  - Anxiety is slightly reduced once patients decide to treat
- The majority (86%) of respondents chose to delay on-demand treatment administration
- The most common reason respondents chose for delaying on-demand treatment was that they questioned whether the attack was severe enough to treat (88%), followed by not carrying their on-demand treatment with them when away from home (53%)
- Nearly all respondents (95%) reported that their level of anxiety decreases once they realize they are recovering from the HAE attack
- This survey, combined with previous insights from patients and healthcare providers, helped develop a conceptual model of the "HAE attack journey" (**Figure 2**)

## Conclusions

- Results from this survey show that many people with HAE have anxiety and treatment burden associated with parenteral on-demand treatment
- People with HAE often delay administering on-demand treatment with longer treatment delays reported by those feeling extremely anxious (4.3 hours) vs moderately anxious (1.7 hours)
- Anxiety is reduced when people realize they are beginning to recover from the attack

## Results

**Figure 2. Conceptual model showing anxiety and on-demand treatment burden during an HAE attack**



- Based on patient feedback, the conceptual model illustrates fluctuations in anxiety levels and treatment burden, starting with an increase at attack recognition followed by a slight reduction in anxiety level at the decision to treat
- Around one-third of patients in the survey report rebound attacks and there is increased anxiety until they feel that the on-demand treatment has halted the attack, eventually subsiding with recovery

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