

Anxiety in Patients Using Injectable On-Demand Treatments for Hereditary Angioedema Attacks: Results from an International Patient Survey

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Rationale

- A high prevalence of anxiety has been reported among patients with hereditary angioedema (HAE)¹
- Injectable on-demand treatments for managing HAE attacks can be painful and challenging to administer and may contribute to high levels of treatment-related anxiety²⁻⁴
- This study aimed to quantify levels of anxiety associated with the use of parenteral on-demand therapy

Methods

- Patients ≥12 years with Type 1 and 2 HAE due to C1 inhibitor deficiency (HAE-C1INH) were recruited by ITACA (IT), US HAEA (US), HZRM and Charité – Universitätsmedizin (DE), HAEUK (UK), and AMSAO (FR) to complete an online survey between April 2023 and October 2025
- Respondents were ≥12 years old and had to have treated ≥1 HAE attack within 3 months* prior to the survey with an approved on-demand therapy
- Respondents rated their anxiety using an 11-point General Anxiety Numeric Rating Scale ranging from 0 “not anxious” to 10 “extremely anxious” to answer the question “How much anxiety did you feel about treating this HAE attack with on-demand treatment?”

*Within 6 months for France.

Results

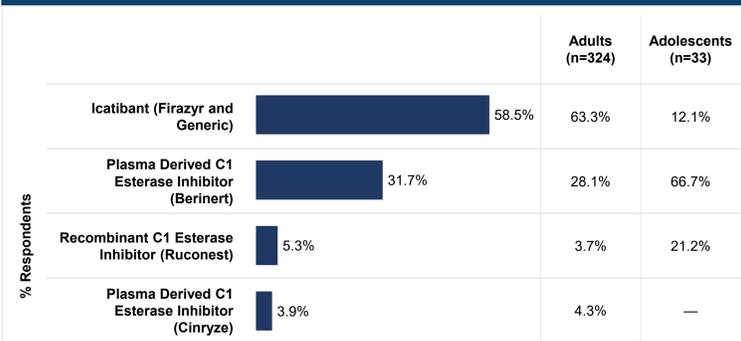
Table 1. Respondent Characteristics

	Total (n=357)	Adults (n=324)	Adolescents (n=33)	On-Demand IV (n=146)	On-Demand SC (n=211)
Current age; years mean (SD)	41.2 (16.3)	44.0 (14.6)	14.3 (1.6)	35.7 (16)	45 (15.6)
Age of diagnosis; years mean (SD)	17.8 (13.6)	19.0 (13.7)	6.0 (3.7)	13.8 (12.1)	20.6 (14.0)
Gender					
Male	32.2%	29.6%	57.6%	29.5%	34.1%
Female	67.5%	70.1%	42.4%	69.9%	65.9%
Country, n (%)					
Italy	101 (31.8%)	87 (26.9%)	14 (42.4%)	46 (31.5%)	55 (26.1%)
United States	94 (29.6%)	80 (24.7%)	14 (42.4%)	31 (21.2%)	63 (29.9%)
Germany	73 (23.0%)	71 (21.9%)	2 (6.1%)	41 (28.1%)	32 (15.2%)
United Kingdom	48 (15.1%)	46 (14.2%)	2 (6.1%)	25 (17.1%)	23 (10.9%)
France	41 (12.9%)	40 (12.4%)	1 (3.0%)	3 (2.1%)	38(18.0%)
HAE Type*					
Type I	89.1%	89.5%	84.8%	91.8%	87.2%
Type II	8.4%	8.0%	12.1%	6.2%	10.0%
Patients taking long-term prophylaxis (%)	57.4%	56.5%	66.7%	62.3%	54.0%
Days since last attack, mean (SD)	22.9 (21.8)	23.1 (21.7)	20.8 (23.1)	20.5 (20.5)	24.6 (22.6)

*2.5% had either Type 1 or Type 2 but reported specific type was unknown

- Respondents included 357 patients (68% female [n=241], 89% Type 1 [n=318]) from Italy (n=101), the US (n=94), Germany (n=73), the UK (n=48), and France (n=41)

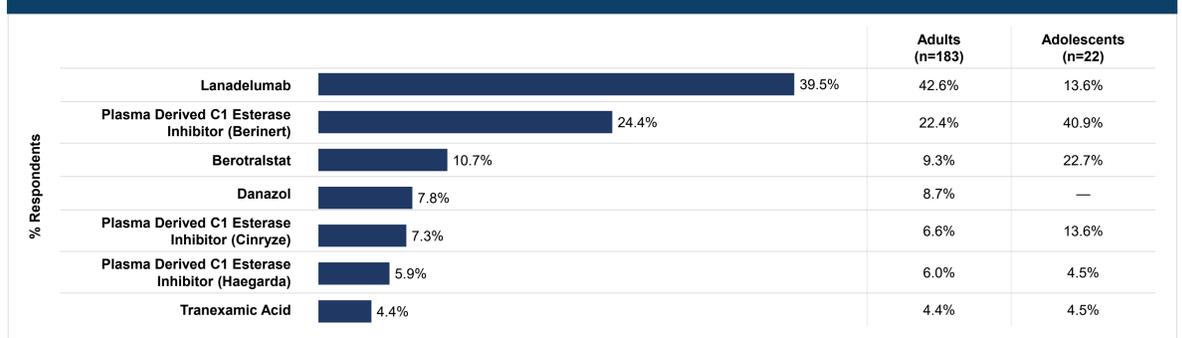
Figure 1. On-Demand Therapy Used for Last Treated Attack



- For their last attack, 41% (n=146) of participants used intravenous (IV) on-demand treatment and 59% (n=211) used subcutaneous (SC) treatment
 - 63.3% of adults and 12.1% of adolescents used SC on-demand treatment

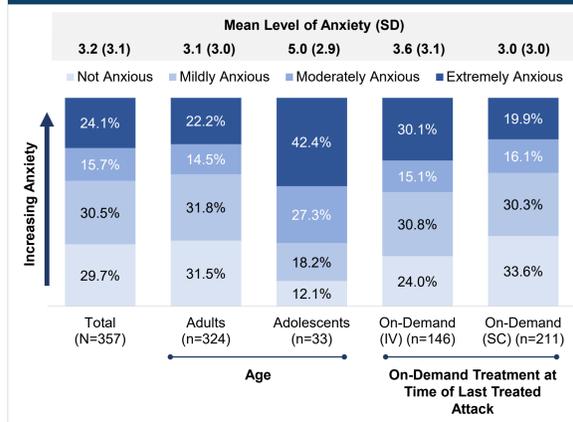
Results

Figure 2. Long-term Prophylaxis Used at Time of Last Treated Attack (n=205)



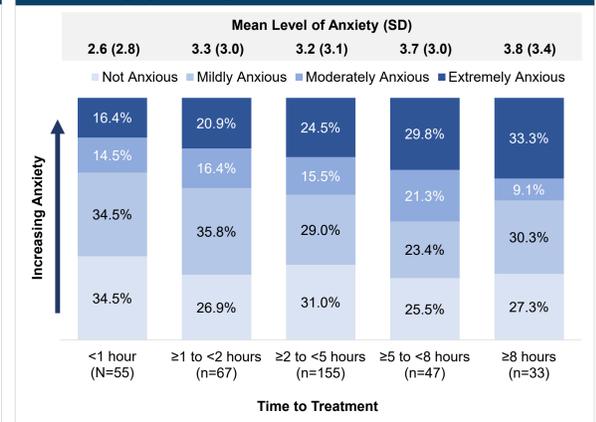
- Of the respondents using long-term prophylaxis, most adults reported using lanadelumab while Berinert was most commonly reported by adolescents

Figure 3. Anxiety about Treating with On-Demand Treatment



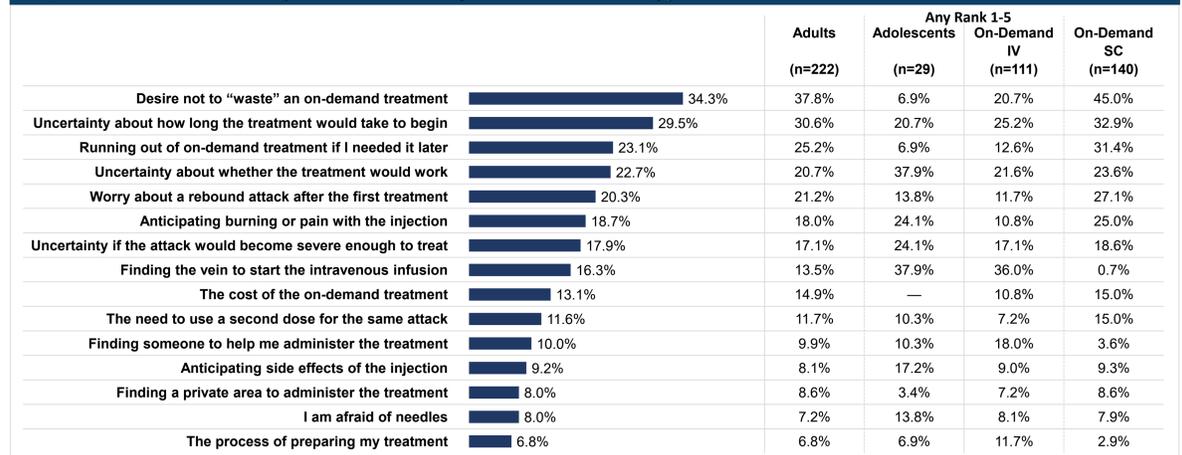
- Seventy percent reported feeling anxious about using injectable on-demand treatment and 24% felt extremely anxious (rating of 7-10)
- Mean anxiety was ≥3.0 for each subgroup, but was higher for adolescents and those taking IV treatment

Figure 4. Time to On-Demand Treatment and Anxiety (n=251)



- Higher anxiety was associated with longer time to treatment

Figure 5. Reasons for Anxiety Associated with On-Demand Treatment (n=251; includes only those who experienced anxiety)



- For adolescents (38%) and IV users (36%), finding a vein to start infusion was the most common reason for anxiety related to treatment administration
- For adults (18%) and SC users (25%), concern about burning/pain with injection was the most common reason for anxiety related to treatment administration

Conclusions

- Seventy percent of respondents experienced anxiety, including 24% with extreme anxiety, due to anticipated use of parenteral on-demand treatment
- While extreme anxiety was more common for IV users (30%), 20% of SC also experienced extreme anxiety
- Greater levels of anxiety were associated with longer treatment delays
- Effective oral alternatives to injectable treatments could potentially address treatment-related anxiety associated with HAE attacks

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