

# Anxiety Associated with On-Demand Treatment for Hereditary Angioedema (HAE) Attacks

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## Background

- Hereditary angioedema (HAE) is a rare genetic disease associated with unpredictable, painful, and debilitating attacks of tissue swelling in various locations of the body that can be life-threatening depending on the location(s) affected
- Global HAE treatment guidelines recommend that people living with HAE should consider treating all attacks early upon recognizing them in order to reduce both the severity and duration of each attack<sup>1-3</sup>
  - Although long-term prophylaxis (LTP) effectively reduces attack frequency, it does not replace the need for on-demand treatment
- All currently approved on-demand treatment options require parenteral administration, which can be challenging to administer and is, thereby, associated with treatment burden
- The current study aimed to characterize anxiety related to the acute use of parenteral on-demand therapy for HAE attacks

## Methods

- The US Hereditary Angioedema Association recruited patients with Type 1 or 2 HAE between April and June 2023
  - Recruitment was stratified to include 50% of patients taking on-demand only and 50% receiving LTP plus on-demand
- Participants completed a 20-minute, self-reported, online survey that asked about their last treated HAE attack
- Participants were ≥12 years old and had to have treated ≥1 HAE attack within the prior 3 months using an approved on-demand therapy

## Results

Table 1. Participant Demographics

	Total (N=94)	On-Demand Only Treatment (46%   n=43)	On-Demand Treatment + LTP (54%   n=51)	Adults (85%   n=80)	Adolescents (15%   n=14)
Current Mean Age, (SD)	39.4 (17.4)	42.6 (18.7)	36.7 (15.8)	43.8 (15.0)	14.4 (1.5)
Mean Age of Diagnosis, Years (SD)	18 (12.6)	19 (12.7)	17 (12.5)	20 (12.5)	6 (4.1)
Gender					
Male	28%	23%	31%	21%	64%
Female	72%	77%	69%	79%	36%
Race/Ethnicity					
White	87%	91%	84%	89%	79%
Hispanic or Latino	9%	2%	14%	8%	14%
Black/African American	3%	2%	4%	3%	7%
American Indian or Alaskan Native	2%	2%	2%	–	14%
Asian	3%	5%	2%	4%	–
Other	1%	–	2%	1%	–
HAE Type					
Type 1	81%	79%	82%	81%	79%
Type 2	19%	21%	18%	19%	21%

### Acknowledgments

The authors wish to thank Jason Allaire, PhD of Generativity Health Outcomes Research for his assistance with this poster. Funding for Dr. Allaire was provided by KalVista Pharmaceuticals.

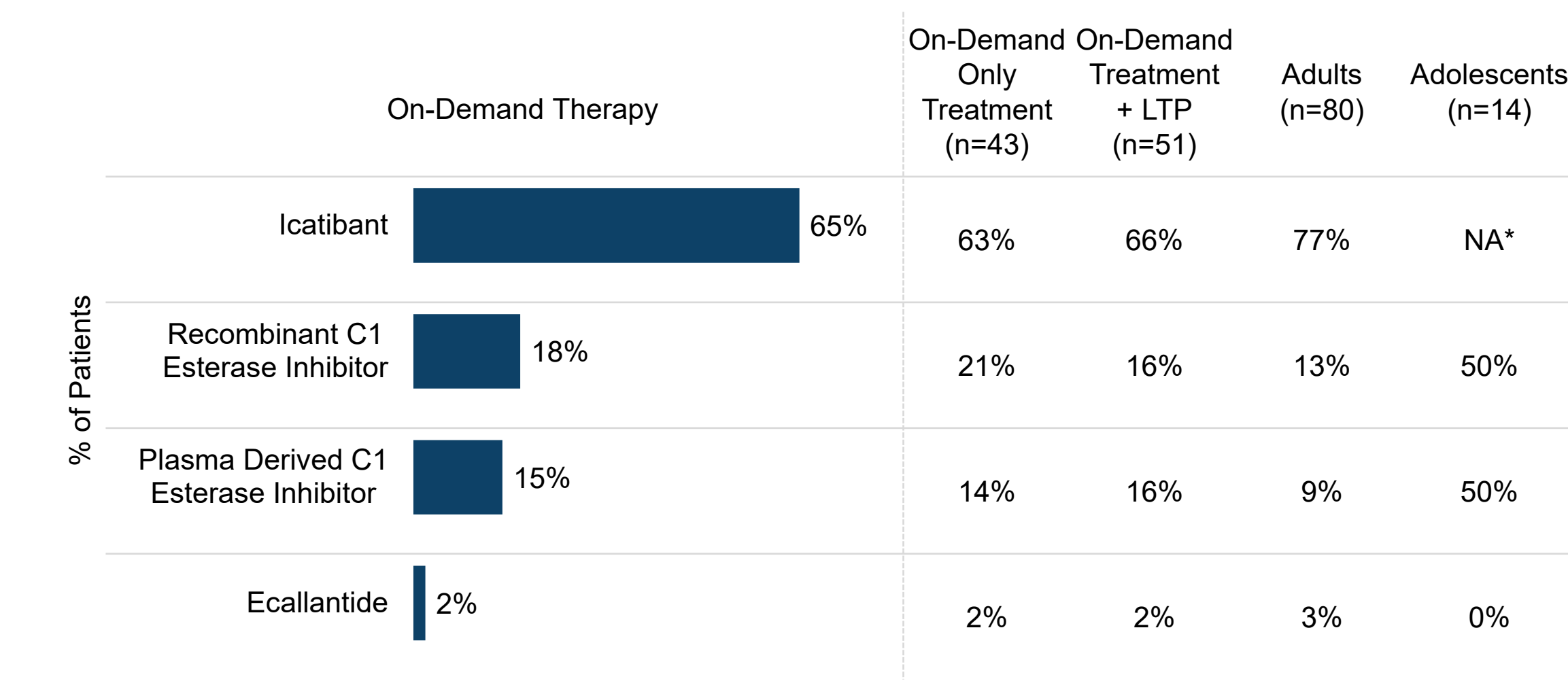
### Disclosures

James Wedner has nothing to disclose. Cristine Radojicic reports honorarium from the following participation: Medical Advisory Board- KalVista, BioCryst, CSL Behring, Astria. Safety Monitoring Board- Astria, Speakers Bureau- CSL Behring. Julie Ulloa and Sherry Danese have received consulting fees from KalVista. Shawn Czado was an employee of KalVista Pharmaceuticals at the time the study was conducted. Vibha Desai and Paul Audhya are employees and own stock of KalVista Pharmaceuticals. Sandra Christiansen reports advisory boards: KalVista, BioCryst, US HAEA Medical Advisory.

## Results

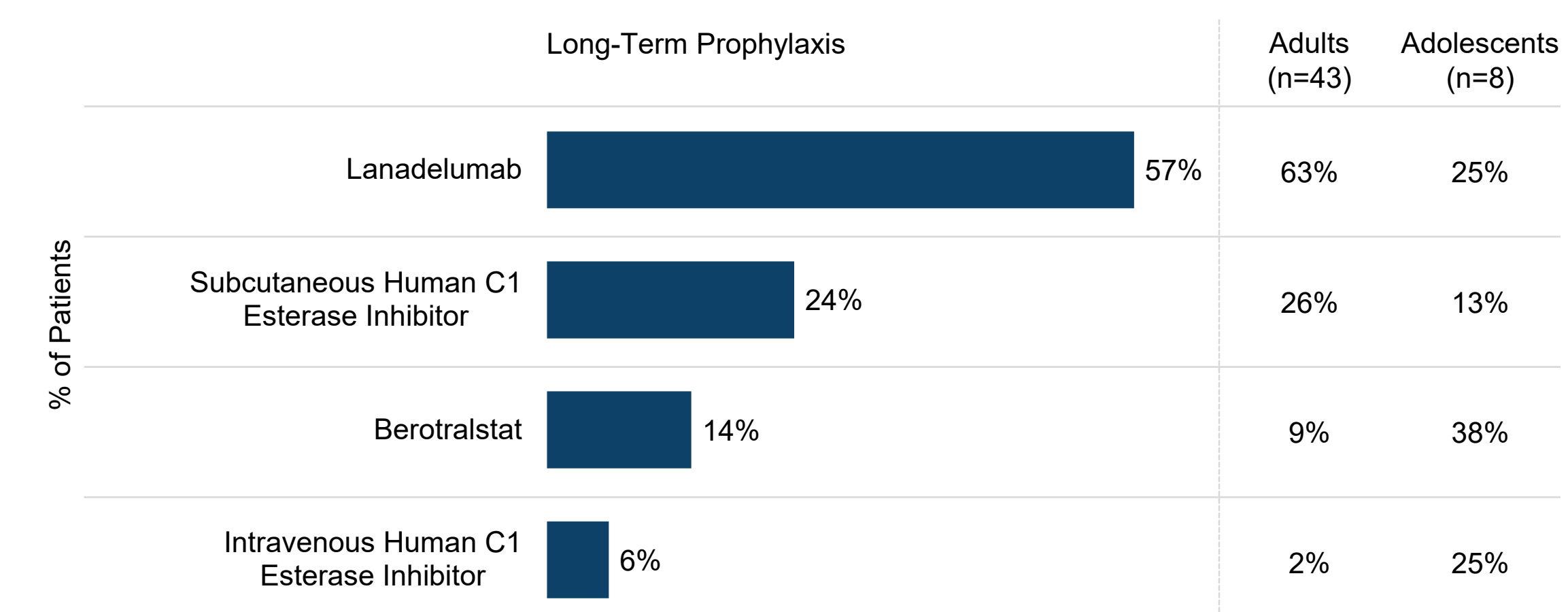
- Respondents included 80 adults and 14 adolescents with an average age of 39 years (Table 1)
- The sample was predominately female (72%) and White (87%)
- At the time of their most recent treated attack, 54% of participants were on prophylaxis, and 46% were using on-demand treatment only
- Most participants (81%) reported having Type 1 HAE

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



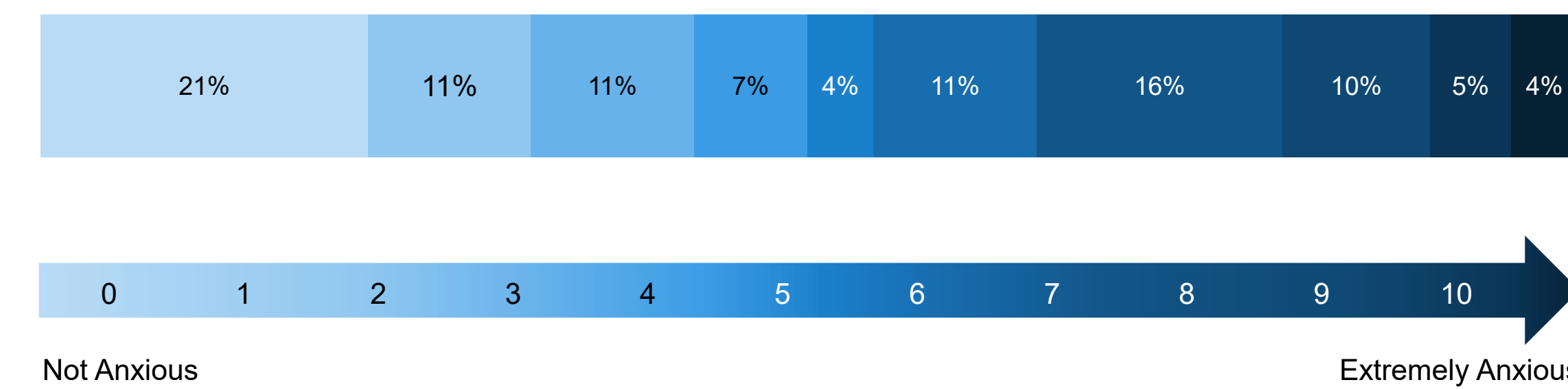
- The initial on-demand treatment was typically icatibant (branded and generic) for adults and recombinant C1 esterase inhibitor or plasma derived C1 esterase inhibitor for adolescents (Figure 1)

Figure 2. Long-term Prophylaxis at Time of Last Treated Attack (n=51)



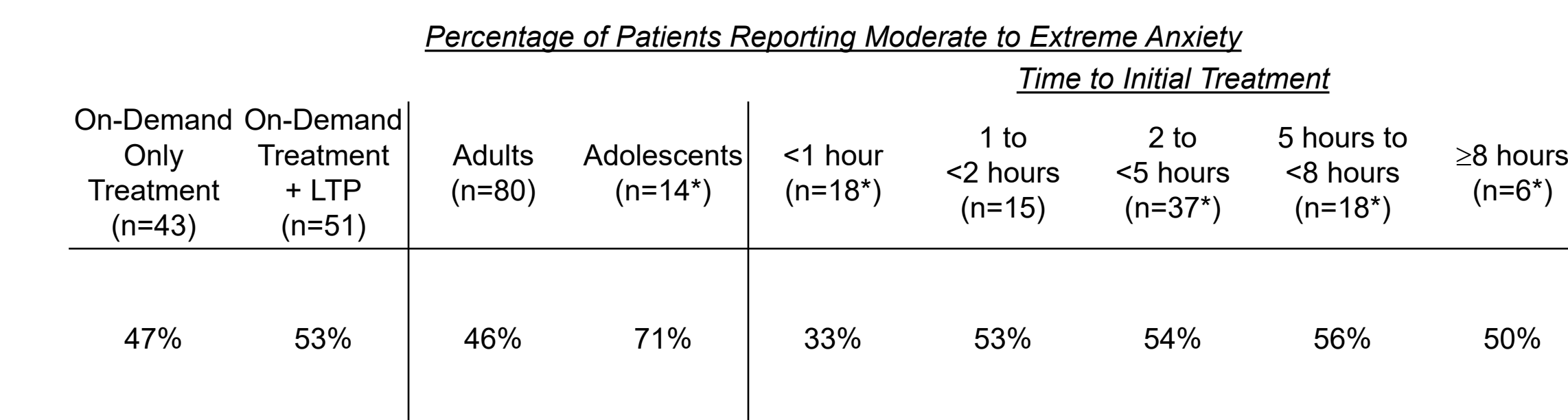
- Among those on long-term prophylaxis at the time of the last treated attack, lanadelumab was the most common treatment among adults, whereas adolescents were most often treated with berotrastat (Figure 2)

Figure 3. Anxiety about Treating with On-demand Treatment



- Mean (SD) anxiety was 4.0 (3.2)
- Overall, 57% reported feeling moderately (4-6 on the anxiety scale) to extremely anxious (7-10 on anxiety scale) about treating their last attack with on-demand treatment (Figure 3)

Figure 4. Patients Reporting Moderate to Extreme Anxiety

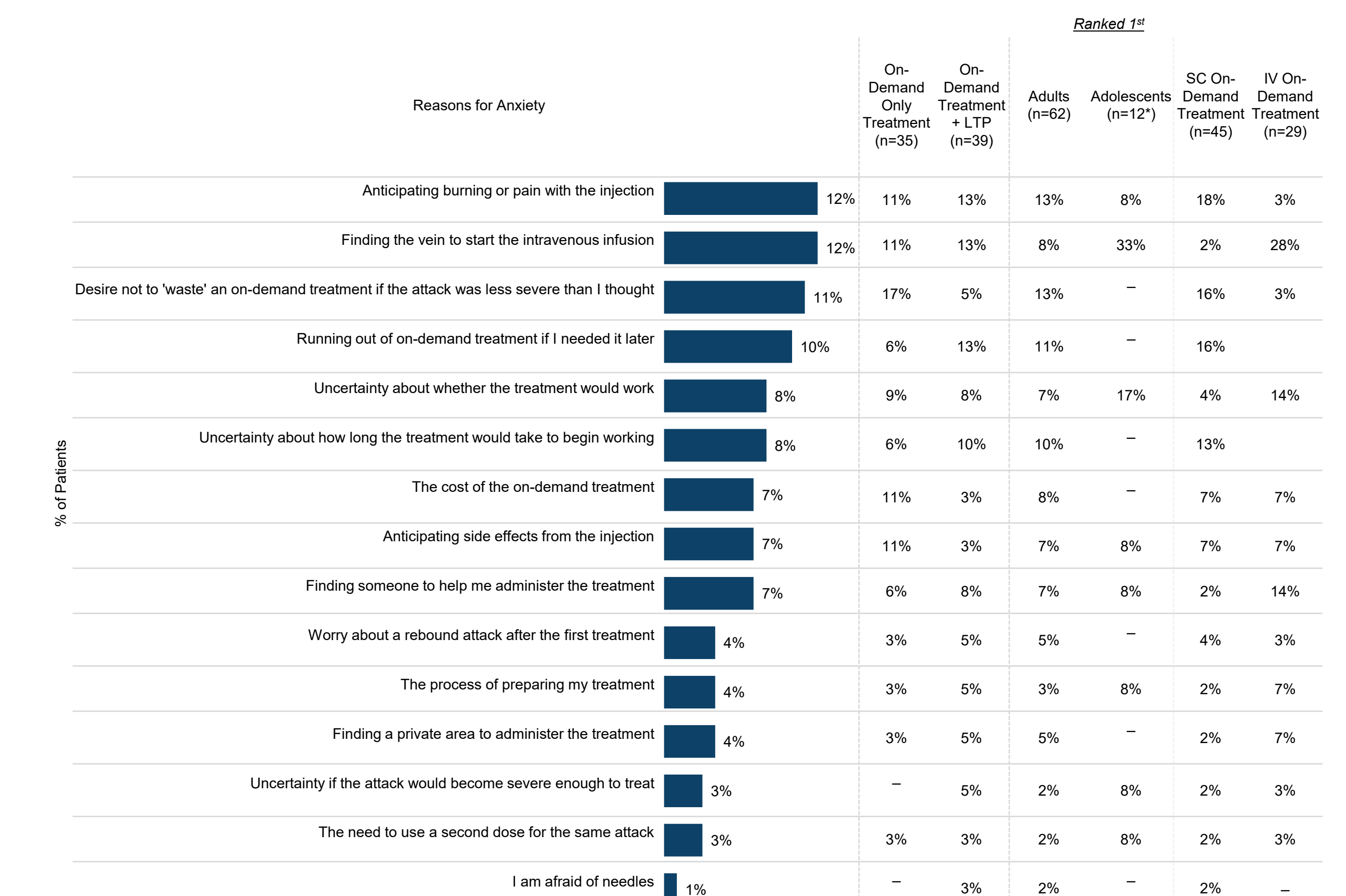


- Patients using on-demand only (47%) and those using on-demand + LTP (53%) had similar levels of moderate to extreme anxiety (Figure 4)
- 71% of adolescents reported moderate to extreme anxiety, compared to 46% of adults
- 54% reported moderate to extreme anxiety when treating in ≥2 hours to <5 hours, compared to 33% when treating within <1 hour from the attack onset
  - Respondents who were extremely anxious were 1.7 times more likely to treat in ≥5 hours rather than in <2 hours compared to those who were not/mildly anxious (95% CI: 0.55-5.44; unadjusted odds ratio)

## Conclusions

- Both adults and adolescents with HAE reported moderate to extreme anxiety when anticipating use of parenteral on-demand treatment, irrespective of use of on-demand only or on-demand plus LTP
- The results of this study highlight the association between delayed treatment and treatment-related anxiety, with a higher proportion of patients who delayed treatment experiencing moderate to extreme anxiety
- Effective non-parenteral alternatives to current on-demand treatments may help to address treatment-related anxiety as a potential barrier to timely treatment

Figure 5. Reasons for Anxiety Associated with On-demand Treatment (n=74)



- The top reason for anxiety associated with treatment reported by on-demand only patients was a desire to not waste on-demand therapy if the attack was less severe (17%), while LTP patients reported pain/burning with injection (13%), finding a vein to start infusion (13%), and running out of on-demand therapy (13%) as their top concerns (Figure 5)
- The top concerns among adults were pain/burning with injection (13%) and a desire to not waste on-demand therapy (13%), while adolescent patients reported finding a vein to start infusion (33%) and uncertainty if the treatment would work (17%) as their top concerns

### References

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### Presented

AAAAI Annual Meeting 2024. February 23-26, 2024 in Washington DC  
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