

# Anxiety Associated with Refilling On-demand Therapy for HAE Attacks Contributes to Treatment Delay and Non-Treatment

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## Abstract

**Rationale:** Hereditary angioedema (HAE) is characterized by painful and debilitating attacks of tissue swelling in various locations. Although self-administered on-demand parenteral (subcutaneous or intravenous) treatment has enhanced HAE attack management, different factors associated with on-demand treatment may contribute to feelings of anxiety. This survey aimed to characterize treatment patterns and anxiety associated with on-demand treatment use, including refilling on-demand treatment.

**Methods:** People with HAE were recruited by the US Hereditary Angioedema Association to complete a 20-minute, self-reported, online survey between September 6 to October 19, 2022.

**Results:** Respondents included 107 Type I and II HAE patients, mean age 41 years, 50% using on-demand therapy only, 50% using first-line prophylaxis plus on-demand therapy. Overall, 86% reported they do not immediately treat all HAE attacks, stating that among the reasons for delayed treatment, 37% did so because of feelings of anxiety related to their ability to quickly refill their on-demand treatment. Of the 69.2% of respondents who reported they do not treat all HAE attacks, 31.1% elected not to treat because they were anxious about their ability to quickly refill their on-demand treatment. This finding was more common for those patients on prophylaxis (43.3%), as compared to those using on-demand therapy only (22.7%). Many (44%) younger patients (<25yrs) and also 38.5% of those <40yrs noted feeling anxiety associated with refilling their on-demand therapy.

**Conclusions:** Results highlight that anxiety associated with not being able to quickly refill on-demand treatment, experienced by people living with HAE, impacts their treatment decisions, contributing to treatment delay or resulting in non-treatment of an HAE attack.

## Rationale

- HAE is characterized by painful and debilitating attacks of tissue swelling in various locations
- Although self-administered on-demand parenteral (subcutaneous or intravenous) treatment has enhanced HAE attack management, different factors associated with on-demand treatment may contribute to feelings of anxiety
- This survey aimed to characterize treatment patterns and anxiety associated with on-demand treatment use, including refilling on-demand treatment

## 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, mean age 41 years (range 16-83); 50% using on-demand therapy only, 50% using prophylaxis + on-demand therapy (Table 1)

Table 1. Respondent characteristics

Characteristic	Total (N=107)
<b>Age, mean (range), years</b>	41 (16-83)
<b>Age category, n (%)</b>	
<25 years	14 (13.2)
≥25 years	93 (86.8)
<40 years	56 (52.3)
≥40 years	51 (47.7)
<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 with on-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>Prophylactic treatments used, n (%) of those using prophylaxis (n=54)</b>	
Lanadelumab	31 (57.4)
Bertralstat	7 (13.0)
C1 esterase inhibitor (subcutaneous)	7 (13.0)
Androgens/steroids	5 (9.3)
C1 esterase inhibitor (intravenous)	4 (7.4)

- Overall, 86% reported they do not immediately treat all HAE attacks (81.5% using prophylaxis + on-demand therapy; 90.6% using on-demand therapy only; Table 2).
- Among the reasons for delayed treatment, 37% indicated feelings of anxiety related to their ability to quickly refill their on-demand treatment (38.6% using prophylaxis + on-demand therapy; 35.4% using on-demand therapy only; Figure 1)
  - 33.3% of patients aged <25 years, 42.2% of those aged 25 to 44 years, and 31.4% of those aged ≥45 years noted feeling anxiety associated with refilling their on-demand therapy quickly

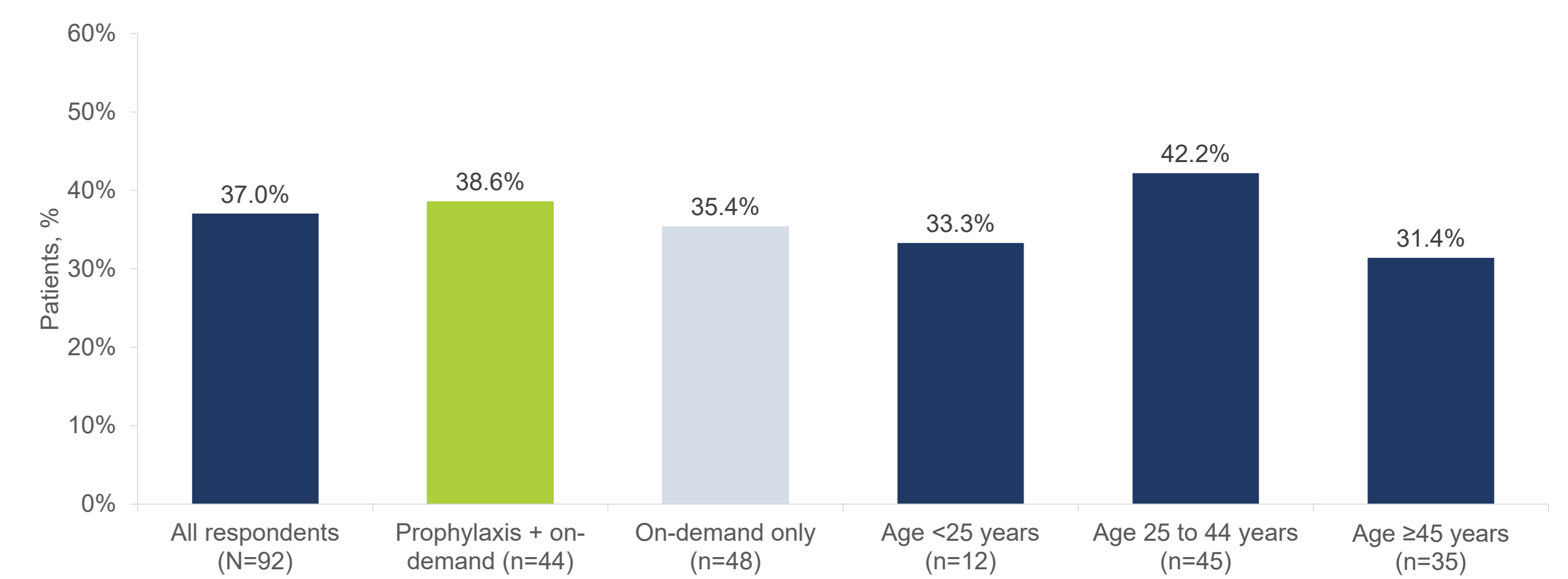
Table 2. Survey question and responses

	Total (N=107)	Prophylaxis + On-demand (n=54)	On-demand Only (n=53)
At first recognition of an HAE attack, do you <b>wait</b> to administer on-demand treatment?			
% "Yes"	86.0%	81.5%	90.6%
% "No"	14.0%	18.5%	9.4%

## Disclosures

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Figure 1. Anxiety associated with refilling on-demand therapy quickly as a reason given for delaying treatment, by those that do not treat immediately (N=92)

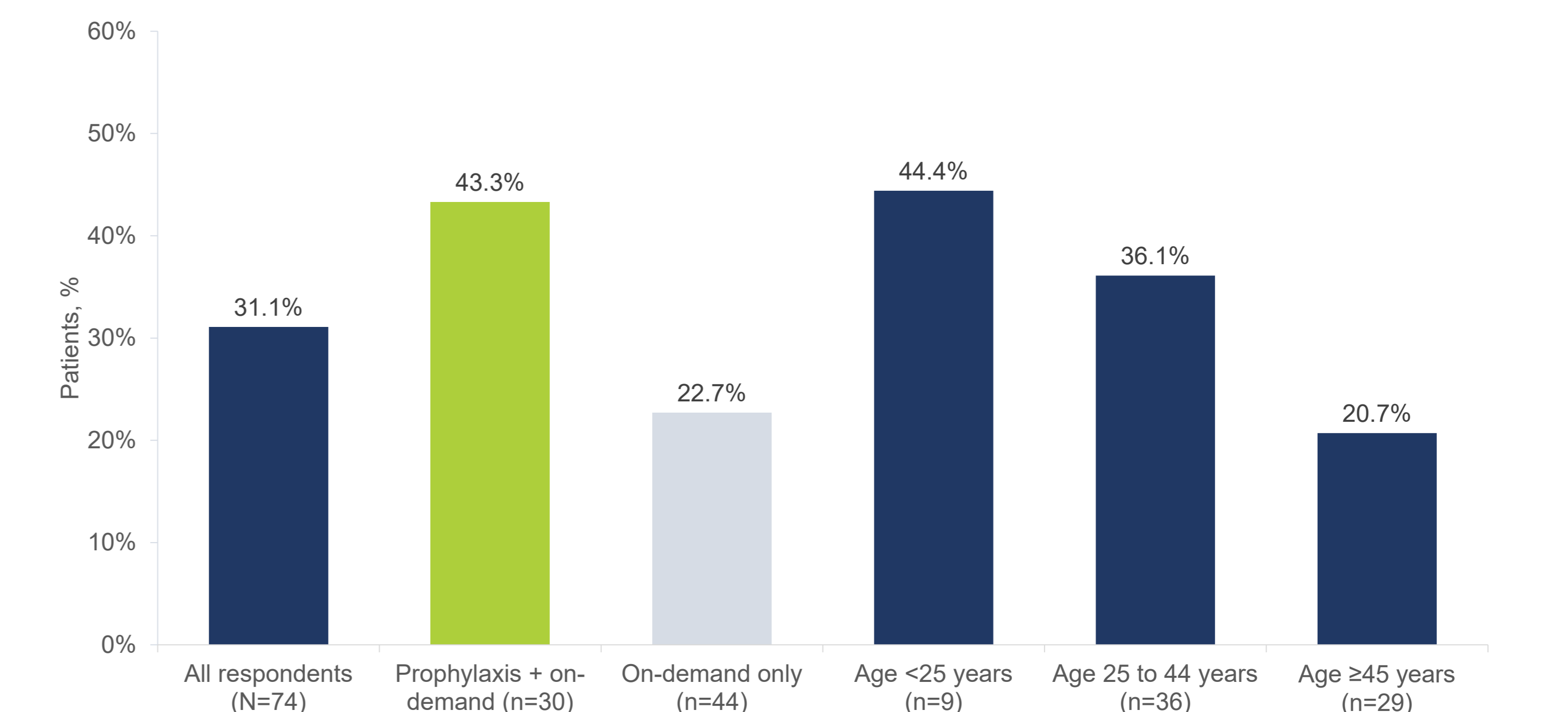


- Of the 69.2% of respondents who reported they do not treat all HAE attacks (Table 3), 31.1% elected not to treat because they were anxious about their ability to quickly refill their on-demand treatment (Figure 2)
  - This finding was more common for those patients on prophylaxis (43.3%) compared with those using on-demand therapy only (22.7%)
  - 44.4% of patients <25 years, 36.1% of those aged 25 to 44 years, and 20.7% of those aged ≤45 years noted feeling anxiety associated with refilling their on-demand therapy quickly

Table 3. Survey question and responses

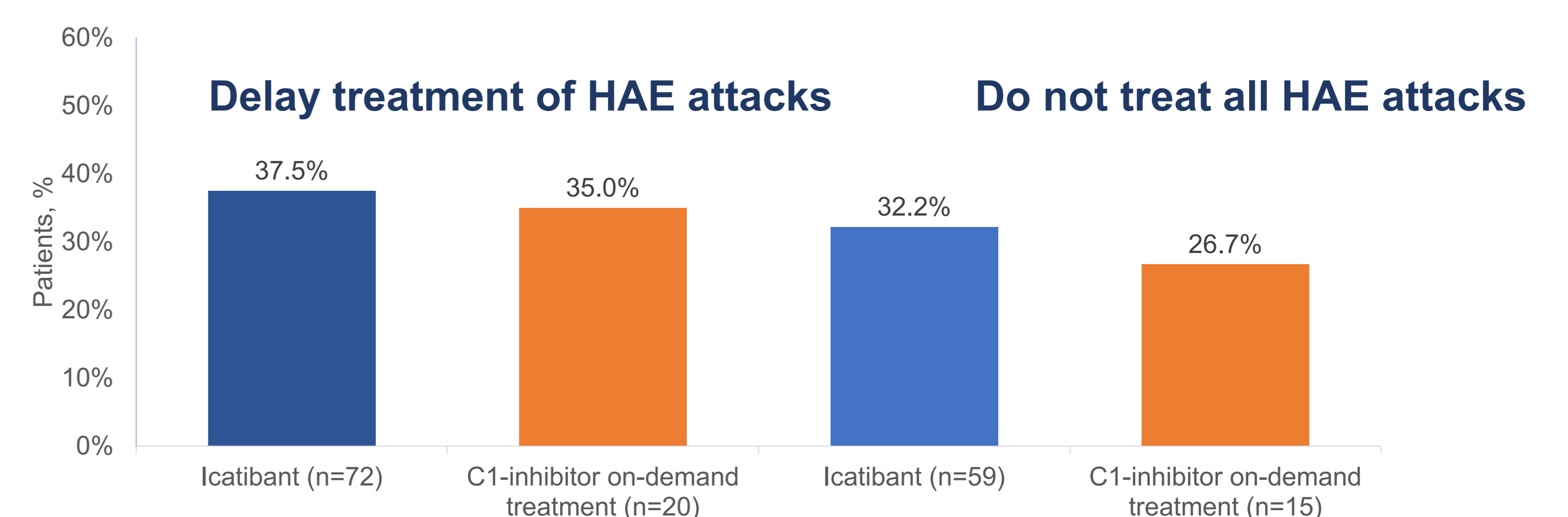
	Total (N=107)	Prophylaxis + On-demand (n=54)	On-demand Only (n=53)
Proportion of respondents that <b>do not</b> treat all of their HAE attacks	69.2%	55.6%	83.0%

Figure 2. Anxiety associated with refilling on-demand therapy quickly as a reason given for not administering treatment, by those that do not treat all attacks (N=74)



- Among patients who delayed treatment or did not treat their HAE attacks due to anxiety about refills, the proportion of patients using icatibant as their on-demand treatment was 37.5% and 32.2%, respectively; proportion of those using other C1-inhibitors was 35.0% and 26.7% (Figure 3)

Figure 3. Anxiety associated with refilling on-demand therapy quickly as a reason given for delaying or not administering treatment, by on-demand treatment used



## Conclusions

- Results highlight that anxiety experienced by people living with HAE associated with not being able to refill on-demand treatment quickly impacts their treatment decisions, contributing to treatment delay or resulting in non-treatment of an HAE attack
- 86.0% of all patients surveyed and 90.6% of those using on-demand therapy only delayed taking on-demand treatment
- People on prophylaxis and those aged <25 years were less likely to treat all HAE attacks due to anxiety associated with refilling on-demand therapy quickly
- The proportion of patients using icatibant as their on-demand treatment that do not treat or who delayed treatment due to anxiety about refills ranged from 32.2% to 37.5% compared with 26.7% to 35.0% for those using other C1-inhibitors

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