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

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### Background

- Hereditary angioedema (HAE) is a rare genetic disease resulting in deficiency (type I) or dysfunction (type II) in the C1inhibitor protein and subsequent uncontrolled activation of the kallikrein-kinin system
- People living with HAE experience unpredictable, painful and debilitating attacks of tissue swelling in various locations of the body that can be life-threatening depending on the location affected
- WAO/EAACI 2021 updated guidelines recommend that all HAE patients
  - consider treating all attacks as early as possible
  - have access to sufficient medication to treat two attacks
  - carry on-demand treatment at all times, regardless of prophylactic therapy
- Although self-administered on-demand parenteral (subcutaneous or intravenous) treatment has enhanced HAE attack management, different factors may contribute to feelings of anxiety leading to delayed treatment or non-treatment of HAE attacks

# Objective

The objective of this analysis was to characterize treatment patterns and anxiety associated with on-demand treatment use, particularly 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 + 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 69% (107/155)
- Respondents provided consent for their data to be used anonymously or in aggregate
- Analysis was performed using descriptive statistics

#### References

Maurer M., et al. The international WAO/EAACI guideline for the management of hereditary angioedema - The 2021 revision and update. World Allergy Organ J. 2022 Apr 7;15(3):100627

#### Disclosures

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# Results

#### Table 1. Respondent characteristics

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Respondents included 107 Type I/II HAE patients, mean age 41 years (range 16-83); 50% using on-demand therapy only, 50% using prophylaxis + on-demand therapy (**Table 1**)

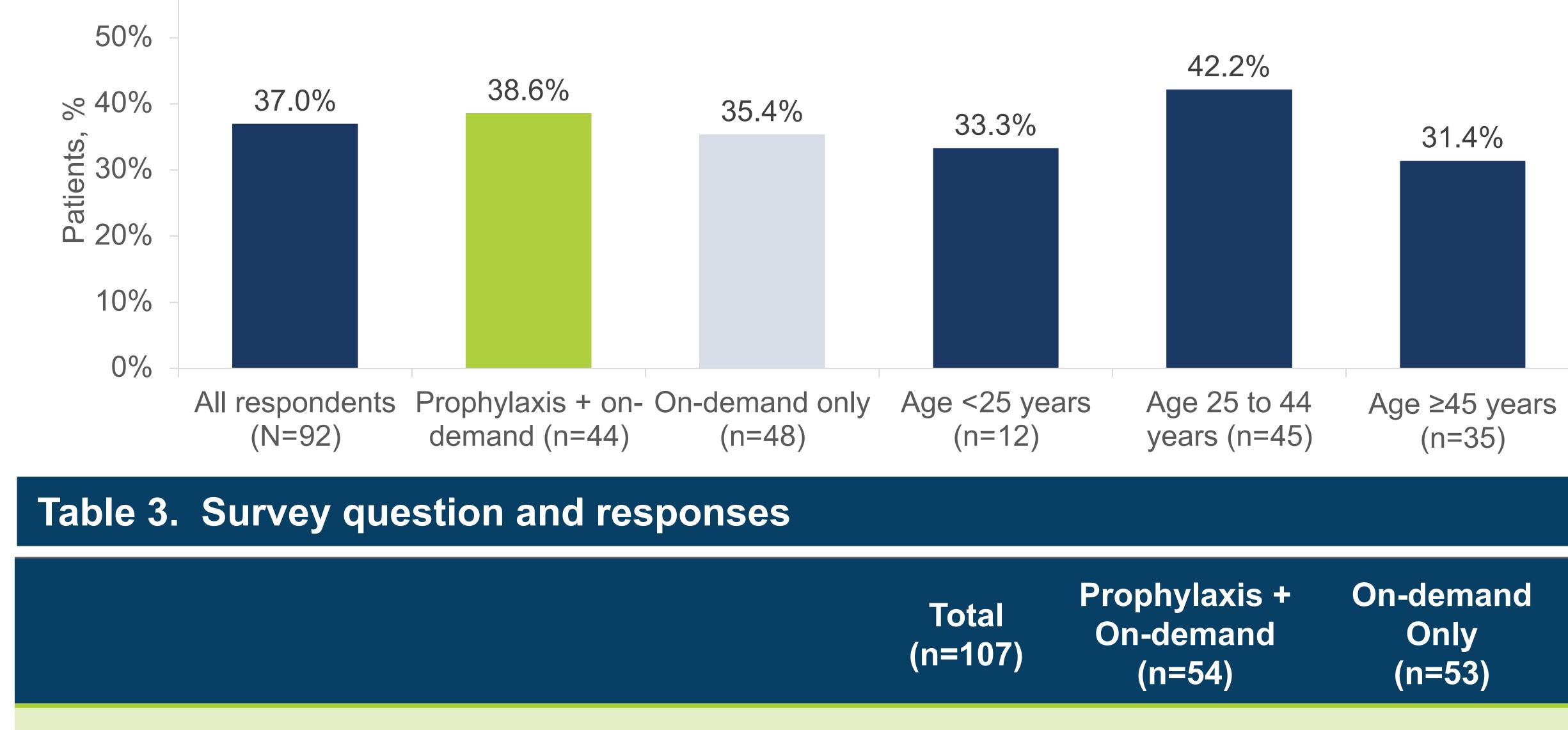
sie i. Respondent characteristics	
acteristic	Total (N=107)
ge, mean (range), years	41 (16-83)
ge category, n (%) <25 years ≥25 years <40 years ≥40 years	14 (13.2) 93 (86.8) 56 (52.3) 51 (47.7)
ender, n (%) Female Male	86 (80.4) 21 (19.6)
<b>pe of therapy, n (%)</b> On-demand only Prophylaxis with on-demand	53 (49.5) 54 (50.5)
<b>n-demand treatments used, n (%)</b> Icatibant C1 esterase inhibitor (recombinant) C1 esterase inhibitor (human) Ecallantide	84 (78.5) 13 (12.1) 9 (8.4) 1 (0.9)
ophylactic treatments used, n (%) of ose using prophylaxis (n=54)	
Lanadelumab Berotralstat C1 esterase inhibitor (subcutaneous) Androgens/steroids C1 esterase inhibitor (intravenous)	31 (57.4) 7 (13.0) 7 (13.0) 5 (9.3) 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**)

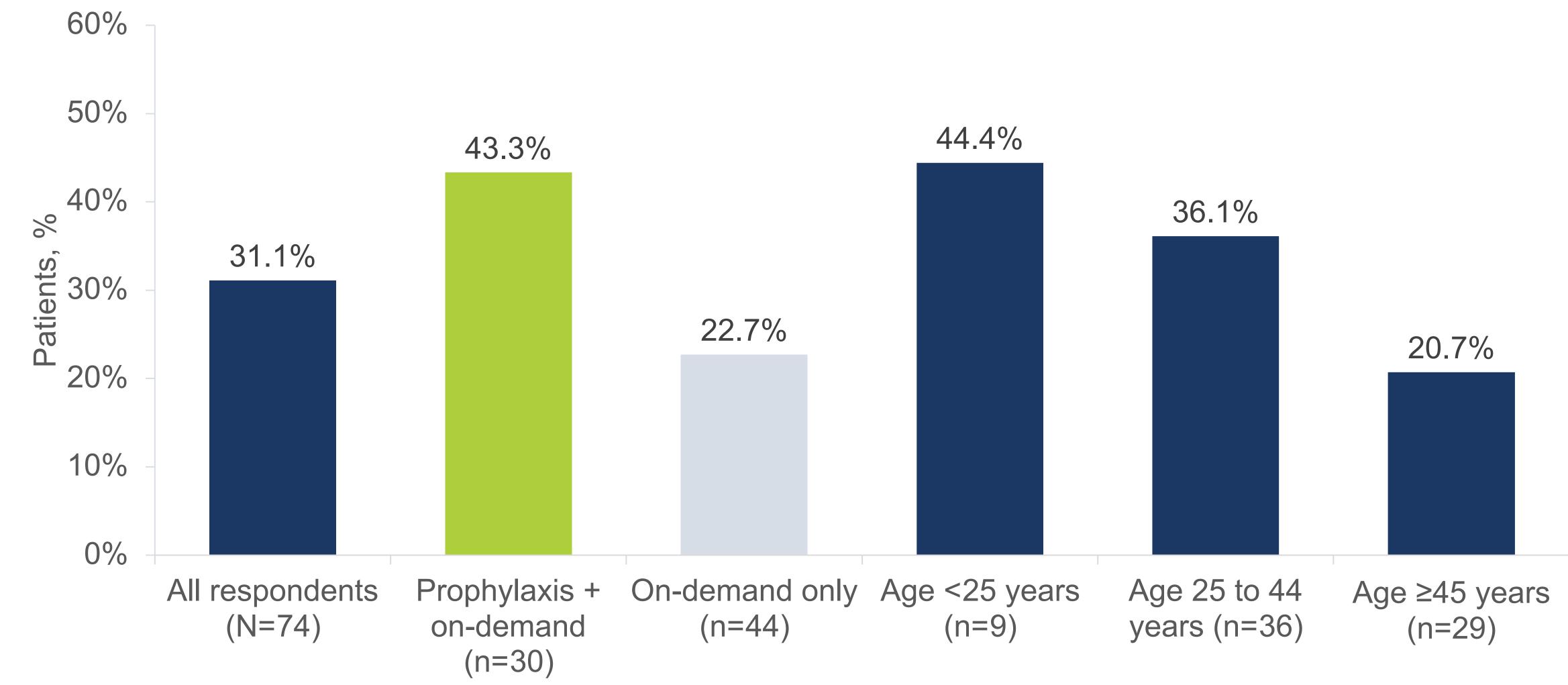
 33.3% of patients aged <25 years, 42.2% of those aged</li> 25 to 44 years, and 31.4% of those aged  $\geq$ 45 years noted feeling anxiety associated with refilling their ondemand therapy quickly

#### Table 2. Survey question and responses On-demand Prophylaxis + Total Only On-demand (n=107) (n=54) (n=53) At first recognition of an HAE attack, do you wait to administer on-demand treatment? 81.5% 90.6% 86.0% % "Yes" 14.0% 18.5% % "No" 9.4%





Proportion of respondents that **do not** treat all of **69.2%%** their HAE attacks



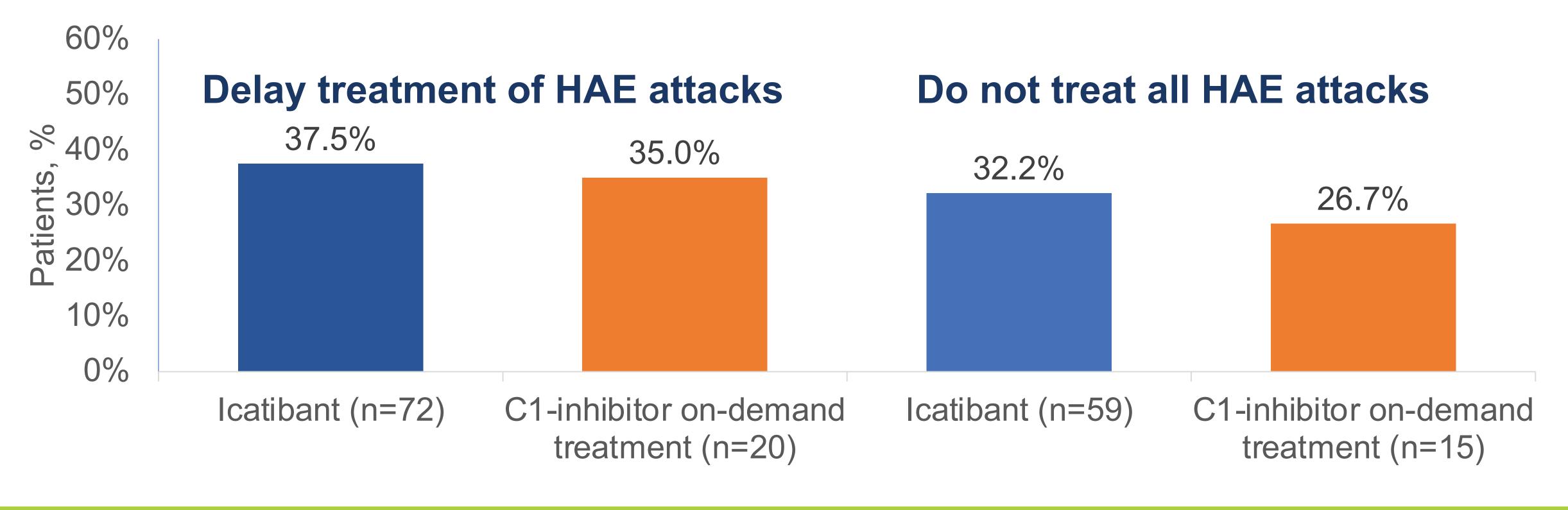
#### Figure 1. Anxiety associated with refilling on-demand therapy quickly as a reason given for delaying treatment, by those that do not treat immediately (N=92)

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)

55.6%

83.0%

- - quickly
- and 26.7% (Figure 3)



# Conclusions

- HAE attack

- inhibitors

 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</li> aged ≤45 years noted feeling anxiety associated with refilling their on-demand therapy

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

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

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

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-



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