



HAE Patients' Decision to Carry On-Demand Treatment When Away from Home

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Background



HAE is characterized by recurrent and unpredictable episodes of subcutaneous or submucosal swelling



Symptoms of an HAE attack can be painful and debilitating, potentially interfering with the ability to conduct daily activities (work, school, social activities)¹



WAO/EAACI 2022 updated guidelines recommend that all HAE patients:²

- 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

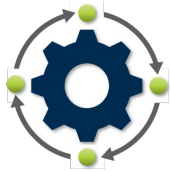


Decisions made by those living with HAE regarding whether to carry their on-demand treatment with them when they leave their home and the motivations behind those decisions have not been well described

1. Bygum A. Hereditary angioedema—consequences of a new treatment paradigm in Denmark. *Acta Derm Venereol.* 2014;94(4):436–41

2. 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.

This survey investigated the perspectives of people living with HAE regarding their decisions to carry on-demand treatment with them when they leave their homes as part of their daily activities



People living with HAE were recruited by the US Hereditary Angioedema Association (HAEA) to complete an online survey

- 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
- Respondents provided consent for their data to be used anonymously or in aggregate

Respondent Characteristics

A total of 107 respondents completed the survey

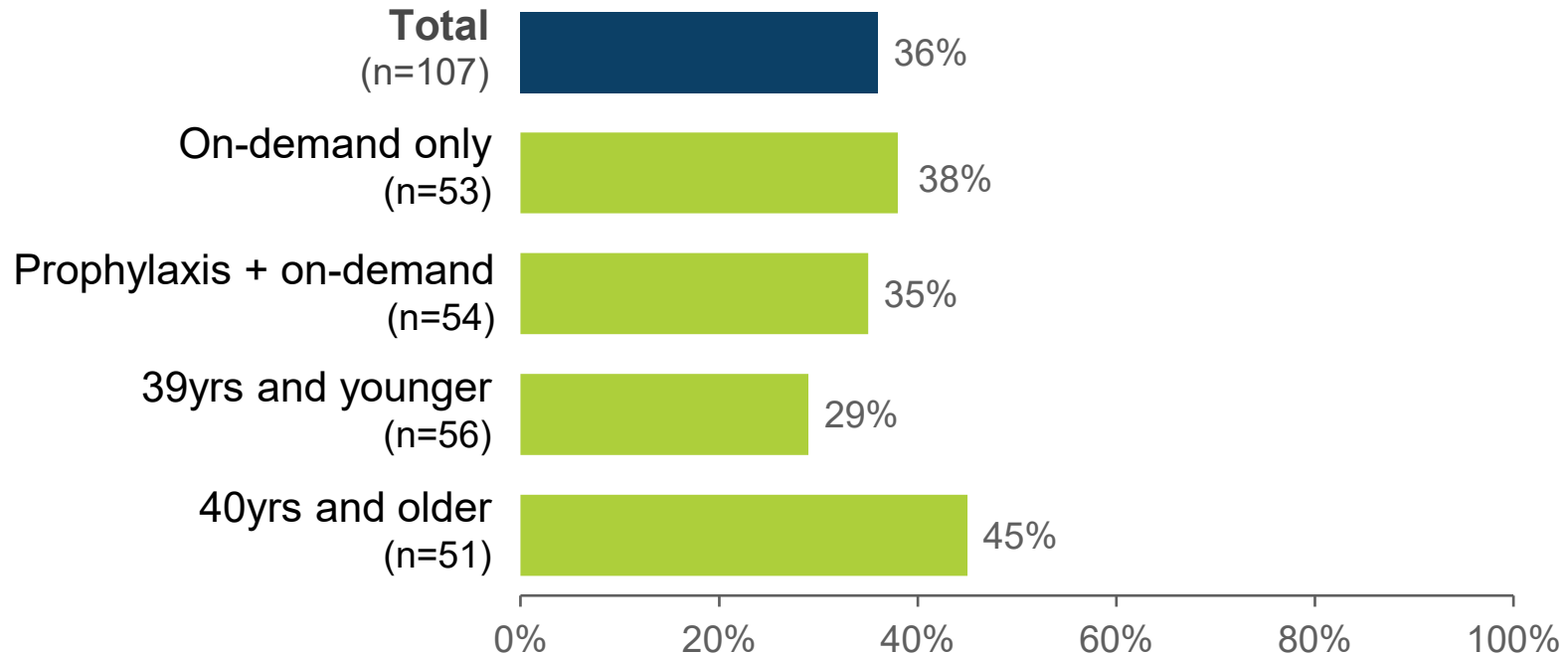
Characteristic	Total (n=107)
Age, mean (SD, range)	41yrs (14.6, 16 to 83)
Age Category, n(%)	
39yrs and younger	56 (52.3%)
40yrs and older	51 (47.7%)
Gender, n(%)	
Female	86 (80.4%)
Male	21 (19.6%)
Type of Therapy, n(%)	
On-demand only	53 (49.5%)
Prophylaxis with on-demand	54 (50.5%)

SD – standard deviation

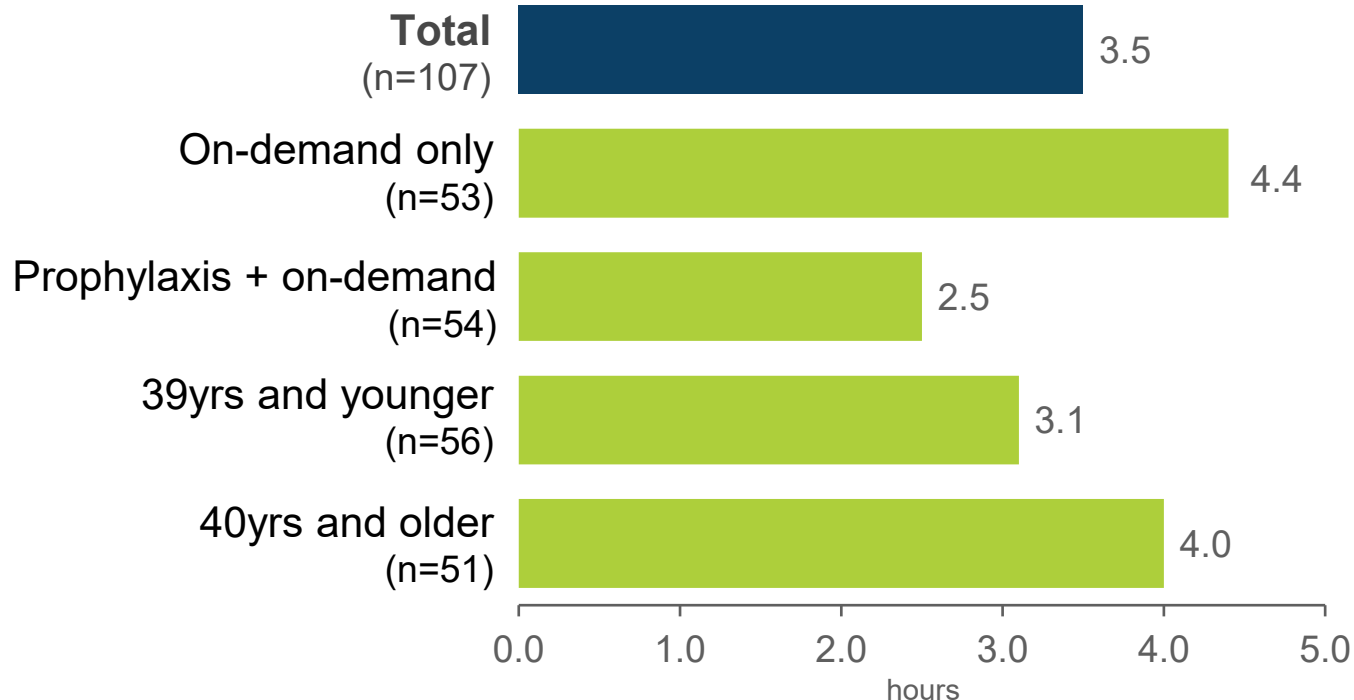
Respondent Characteristics

Treatment	Total (n=107)
Current Primary On-demand treatment, n (%)	
Firazyr/Icatibant	84 (78.5%)
Ruconest	13 (12.1%)
Berinert	9 (8.4%)
Kalbitor	1 (0.9%)
Current Prophylactic treatment, n (%)	
Takhzyro	31 (29.0%)
Haegarda	7 (6.5%)
Orladeyo	7 (6.5%)
Androgens/steroids	5 (4.7%)
Cinryze	4 (3.7%)
Not using prophylactic treatment	53 (49.5%)

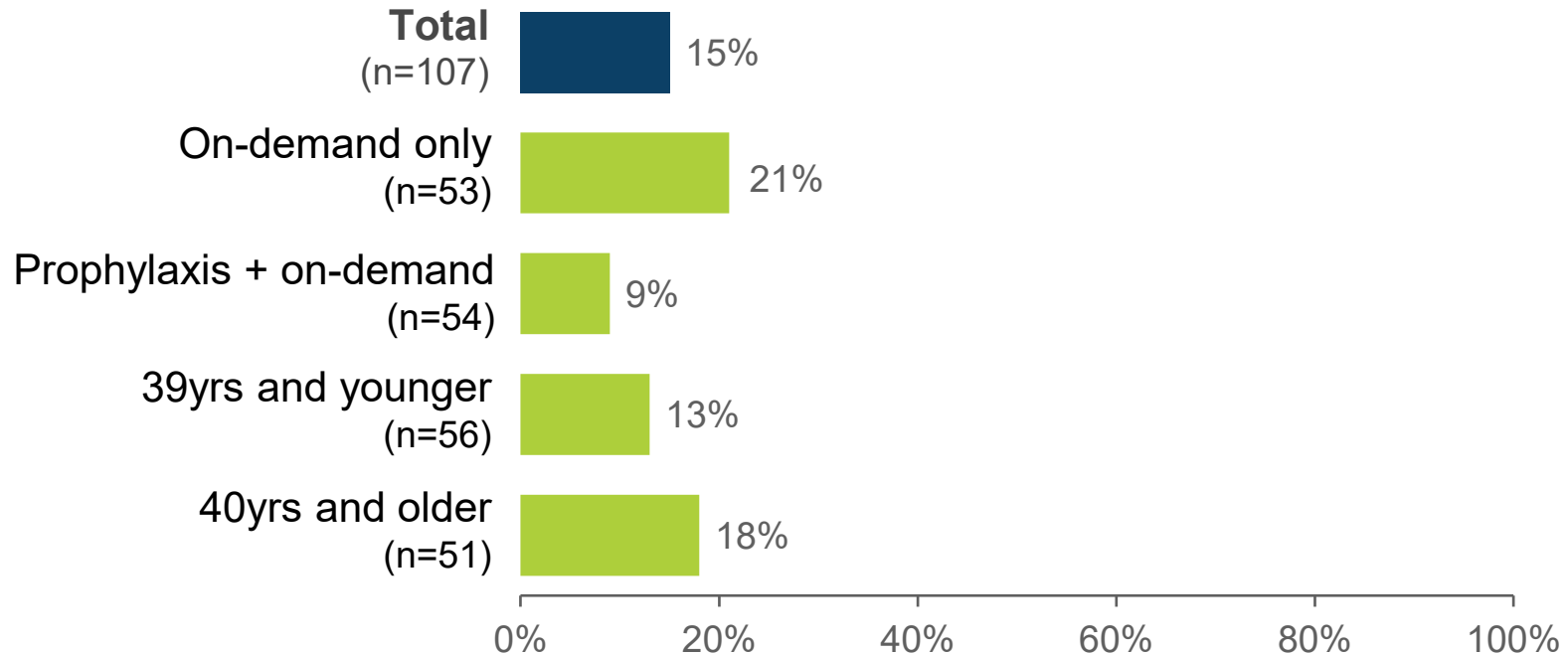
Proportion of respondents who always carry their HAE on-demand treatment with them when they are away from home, as part of their day-to-day life



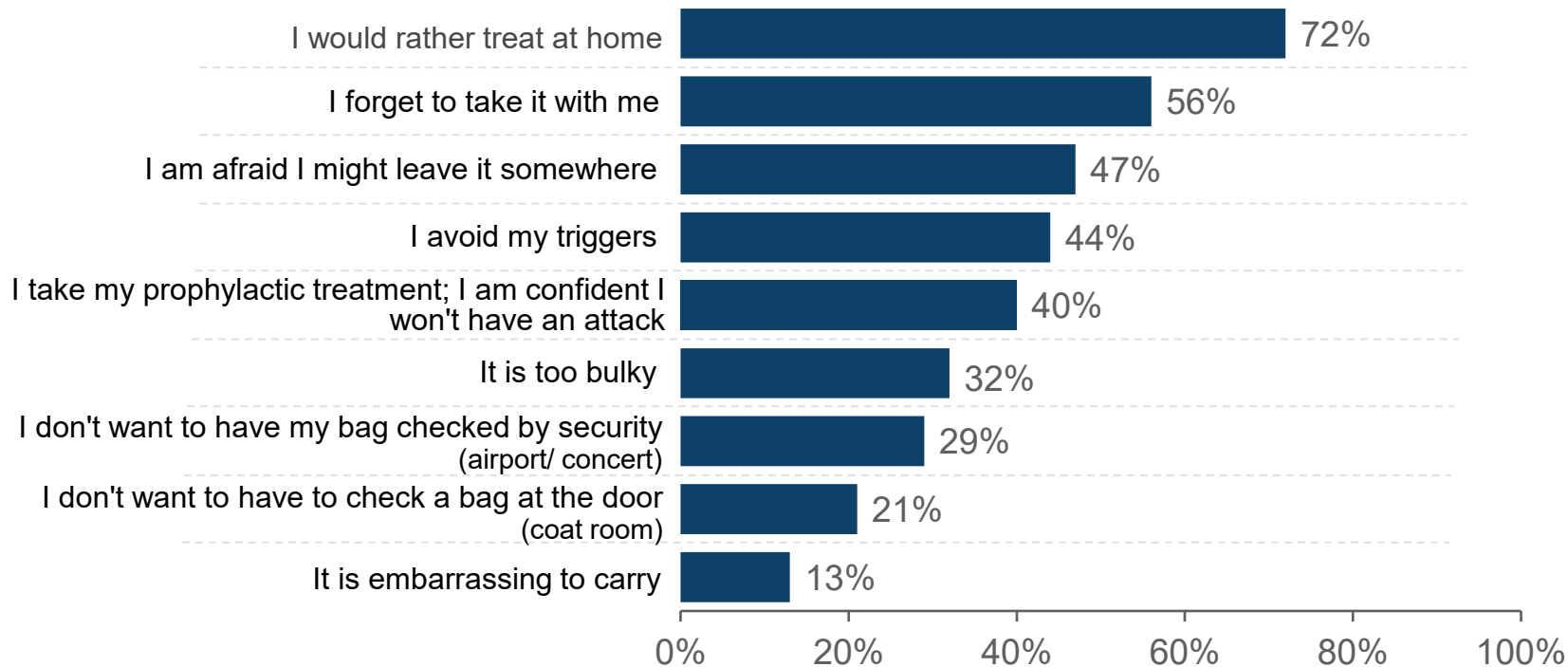
Approximately how long (mean, in hours) respondents will travel away from home without taking on-demand treatment with them



Proportion of respondents who will travel more than 6 hours away from home without taking on-demand treatment with them



Reasons respondents provided for not taking their on-demand treatment with them when they are away from home, as part of their day-to-day life



Conclusions

Results highlight that many HAE patients often make the decision to not carry on-demand treatment with them when they are away from home, missing the opportunity to treat attacks early and optimize treatment outcomes

Patients will travel for several hours away from home without bringing on-demand treatment

Given current on-demand treatment options, HAE patients prefer to avoid triggers and treat their attacks at home

Although there have been clear advancements in treatment options, the promise of self-administered, on-demand therapy, leading to better attack management, has not yet been fulfilled

More research is needed to understand why HAE patients prefer to treat at home and do not carry their on-demand medication



Thank you to all survey participants, and those who assisted in the development of the survey, and participant recruitment