Understanding Why Hereditary Angioedema Patients Often Do Not Carry Their On-Demand Treatment With Them

Bob Geng,¹ Sally van Kooten,² Markus Heckmann,² Sherry Danese,³ Ledia Goga,^{2a} Cristine Radojicic⁴

¹Allergy and Immunology, University of California, San Diego, California, United States; ²KalVista Pharmaceuticals, Inc.; Cambridge, Massachusetts, United States; ³Outcomes Insights; Agoura Hills, California, United States; ⁴Division of Pulmonary, Allergy and Critical Care, Duke University Medical Center, Durham, North Carolina.

^aEmployee of KalVista Pharmaceuticals at the time the study was conducted

Background

- Hereditary angioedema (HAE) is a rare genetic disease resulting in deficiency (type I) or dysfunction (type II) in the C1-inhibitor 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 2022 updated guidelines recommend that all HAE patients¹
- 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
- Early treatment of attacks with on-demand therapy, currently only available parenterally, is critical to reducing the impact and duration of attacks. Prior studies have shown that treatment delay may be related to not having ready access to on-demand treatment (or not carrying on-demand treatment with them)²

Objective

The objective of this analysis was to characterize the reasons patients do not carry their on-demand treatment with them when they leave home, as part of their day-to-day lives

Methods

- The US Hereditary Angioedema Association (HAEA) recruited people living with HAE 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; response rate 69% (107/155)
- Respondents provided consent for their data to be used anonymously or in aggregate
- Analysis was performed using descriptive statistics

- 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.
- Valerieva A., et al. Patients delay treating hereditary angioedema (HAE) attacks with currently available, injectable, on-demand therapies: associated with on-demand treatment of hereditary angioedema (HAE) attacks. Poster presentation. EAACI 2023

Results

asked to indicate the percentage of the time they carry an HAE on-demand treatment with them when

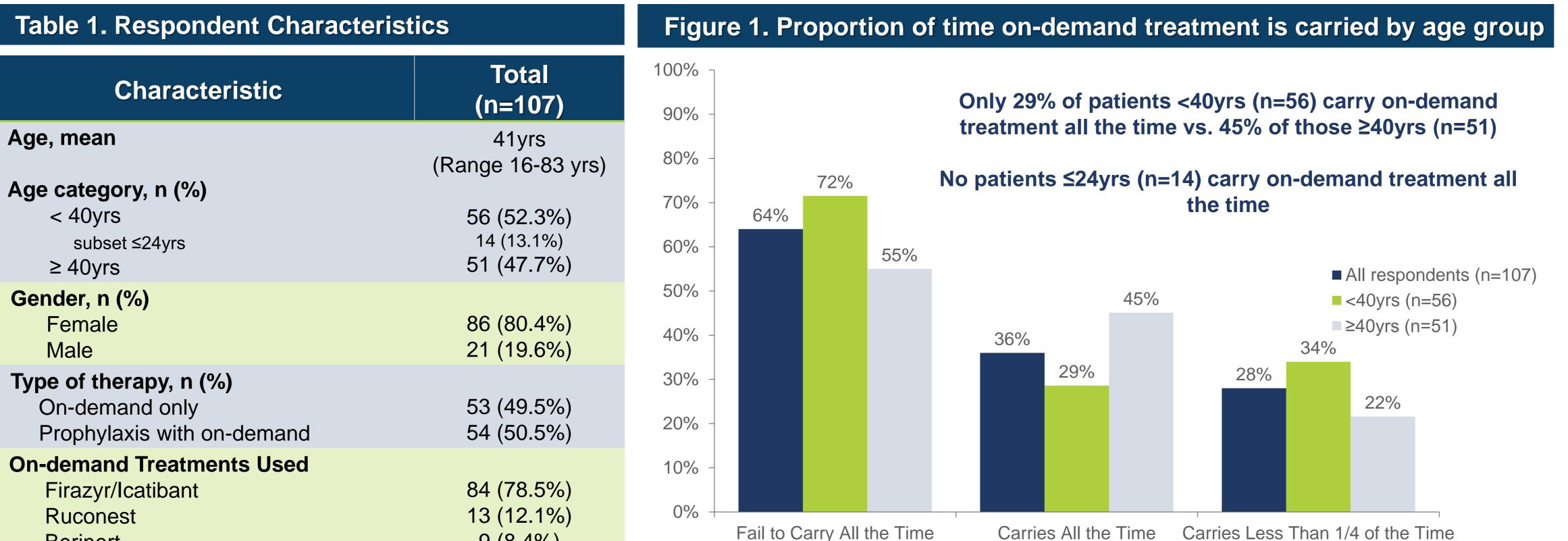


Figure 3. Reasons given for not carrying on-demand treatment at all times, by those that do not always carry (n=68)

9 (8.4%)

1 (0.9%)

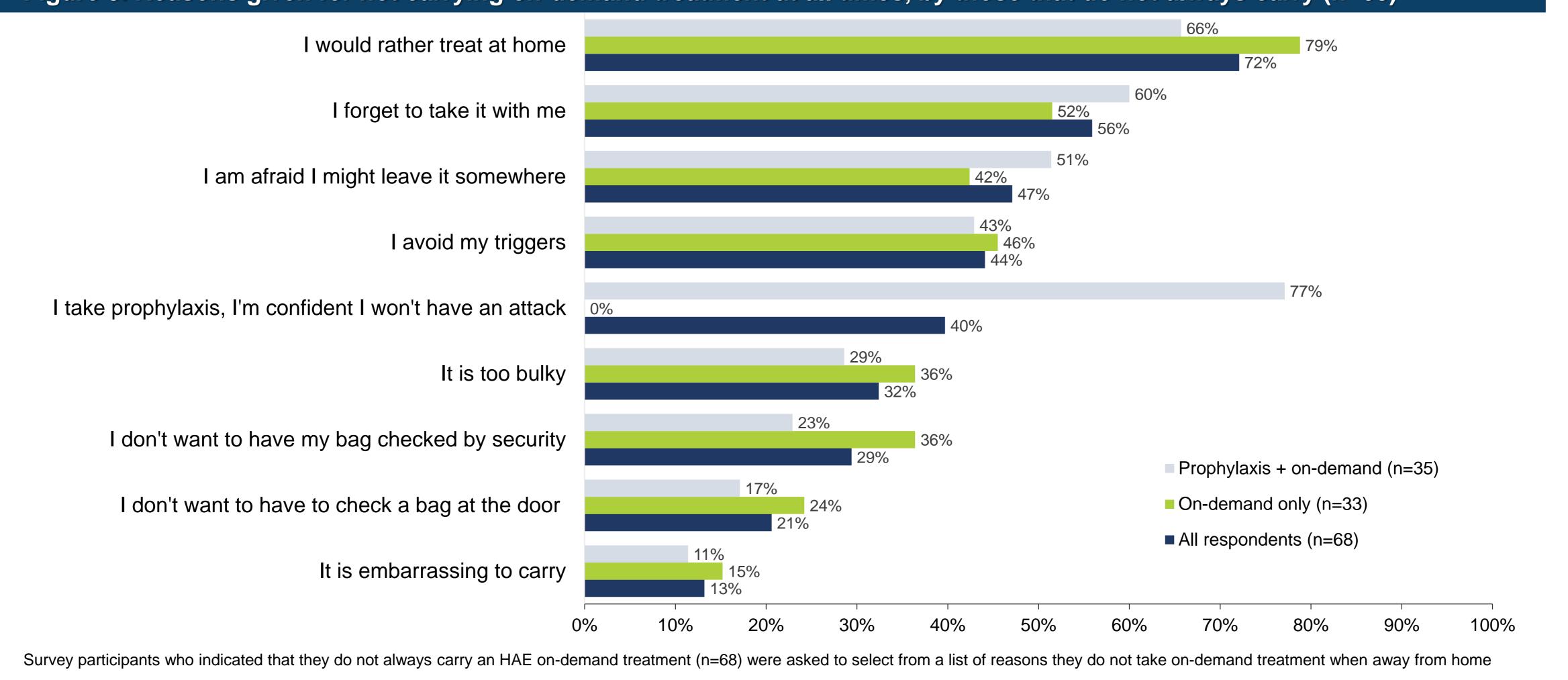
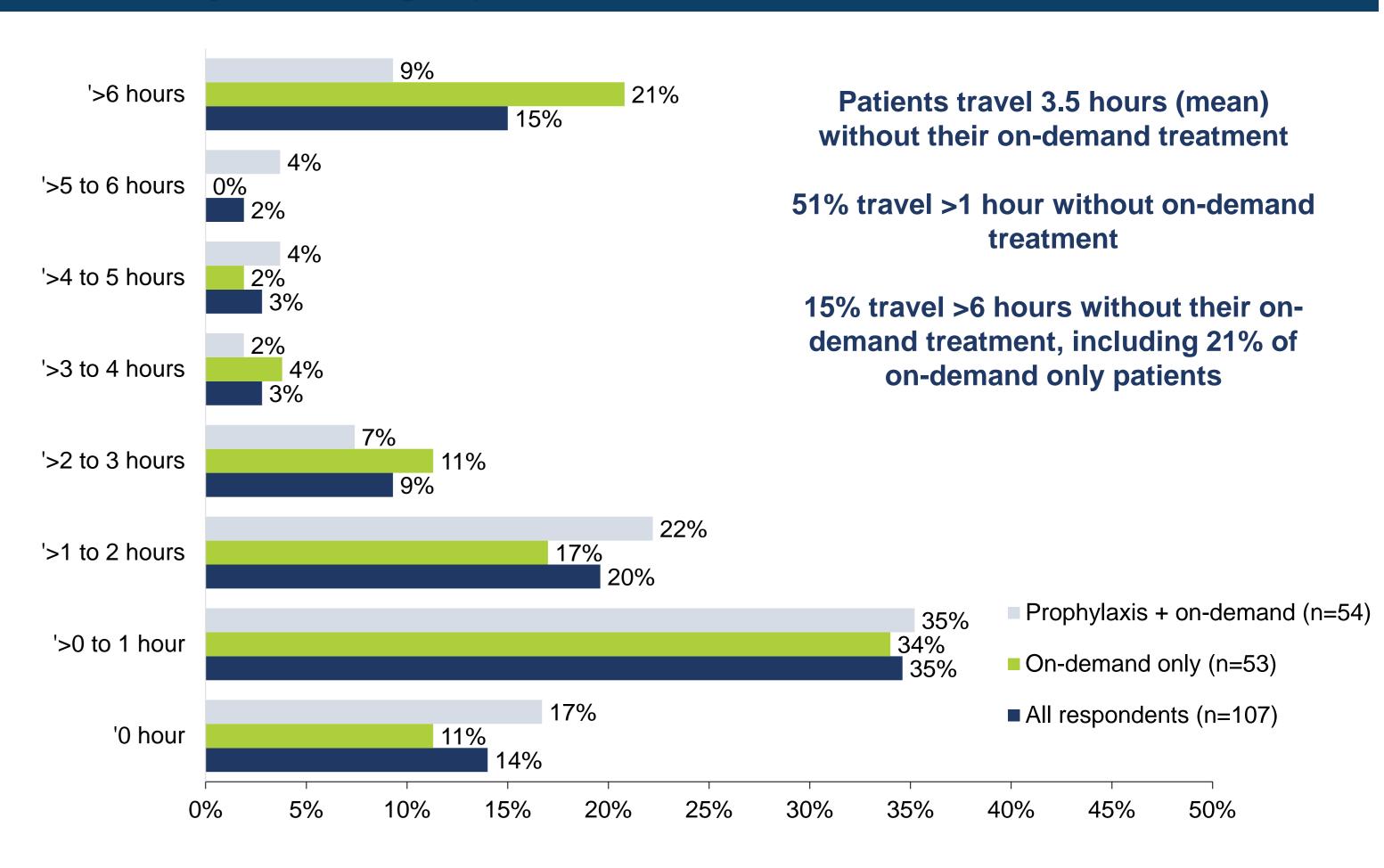


Figure 2. Number of hours people travel away from home without on-demand treatment, by treatment group



Survey participants were asked to indicate approximately how far (time-hours) they will travel from home without taking on-demand treatment with them.

Conclusions

- Survey results highlight that a large proportion of people with HAE do not carry on-demand treatment when leaving home as part of their day-to-day lives, despite guideline recommendations
- More than half the people with HAE in the survey will travel more than one hour away from home without their on-demand treatment and one in five people that only use on-demand treatment (no prophylaxis) will travel more than six hours without their treatment
- These results reflect a significant need to improve patient education related to the importance of carrying on-demand treatment, enabling patients to treat HAE attacks early after attack onset

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^aEmployee of KalVista Pharmaceuticals at the time the study was conducted.

Sally van Kooten, Markus Heckmann and ^aLedia Goga - Employees of KalVista Pharmaceuticals, Inc.

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