

The Impact of On-demand Treatment on Quality of Life of People with HAE

Paula Busse,¹ Bob Geng,² Sally van Kooten,³ Neil Malloy,⁴ Markus Heckmann,³ Julie Ulloa,⁵ Douglas H. Jones⁶

¹Department of Medicine, Division of Clinical Immunology, Mount Sinai, New York, United States; ²Allergy and Immunology, University of California, San Diego, California, United States; ³KalVista Pharmaceuticals, Inc., Cambridge, Massachusetts, United States; ⁴Summit Global Health, United States; ⁵Outcomes Insights, Agoura Hills, California, United States; ⁶Rocky Mountain Allergy at Tanner Clinic; Layton, Utah, United States.

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
- Although self-administered on-demand parenteral (subcutaneous or intravenous) treatment has enhanced overall HAE attack management, the administration of parenteral on-demand therapies may still negatively impact the quality of life (QoL) of those living with HAE

Objective

- The objective of this analysis was to characterize how current parenteral on-demand HAE treatment impacts the QoL of people with HAE

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 only and 50% receiving LTP plus on-demand
- 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

Disclosures

This study was sponsored by KalVista Pharmaceuticals. All authors met the ICMJE authorship criteria and had full access to relevant data. The authors had full editorial control of the data presented and provided final approval of all content. Neither honoraria nor payments were made for authorship.
 Paula Busse - Advisor/Consultant and/or Grant/Research Support: CSL Behring, KalVista Pharmaceuticals, Inc., BioCryst Pharmaceuticals, Takeda, Regeneron, and Novartis
 Bob Geng - Advisory Board/Consultant/Speaker: Amerimmune Allergy Testing, Inc., KalVista Pharmaceuticals, Inc., Pharvaris, Astra-Zeneca, BioCryst Pharmaceuticals, Regeneron/Sanofi, Zurvita Corporation, Pharming, and Shire/Takeda
 Sally van Kooten and Markus Heckmann - Employees of KalVista Pharmaceuticals
 Neil Malloy - Consultant fees from KalVista Pharmaceuticals
 Julie Ulloa - Consultant fees from KalVista Pharmaceuticals
 Douglas H. Jones - Advisory Board/Consultant/Speaker: Amerimmune Allergy Testing, Inc., KalVista Pharmaceuticals, Inc., Pharvaris, Astra-Zeneca, BioCryst Pharmaceuticals, Regeneron/Sanofi, Zurvita Corporation, Pharming, and Shire/Takeda

Results

- 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)

Table 1. Respondent characteristics

Characteristic	Total (N=107)
Age, mean (range), years	41 (16-83)
Age category, n (%)	
<25 years	14 (13.2)
≥25 years	93 (86.8)
<40 years	56 (52.3)
≥40 years	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)
On-demand treatments used, n (%)	
Icatibant	84 (78.5)
C1 esterase inhibitor (recombinant)	13 (12.1)
C1 esterase inhibitor (human)	9 (8.4)
Ecaltantide	1 (0.9)
Prophylactic treatments used, n (%) of those using prophylaxis (n=54)	
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)

- Many patients (48.6%) reported being moderately to extremely anxious (4-10 on anxiety scale of 0-10) when anticipating on-demand treatment administration (Table 2)

Table 2. Reported level of anxiety when anticipating on-demand treatment, n (%)

'Extremely anxious' (7-10 on scale of 0 to 10)	35 (32.7)
'Moderately anxious' (4-6 on scale of 0 to 10)	17 (15.9)
'Mildly anxious' (1-3 on scale of 0 to 10)	36 (33.6)
'Not anxious' (0 on scale of 0 to 10)	19 (17.8)

Participants were asked, "Please rate your level of anxiety when you anticipate using your current on-demand treatment," and provided a scale to select from 0-Not anxious to 10-Extremely anxious

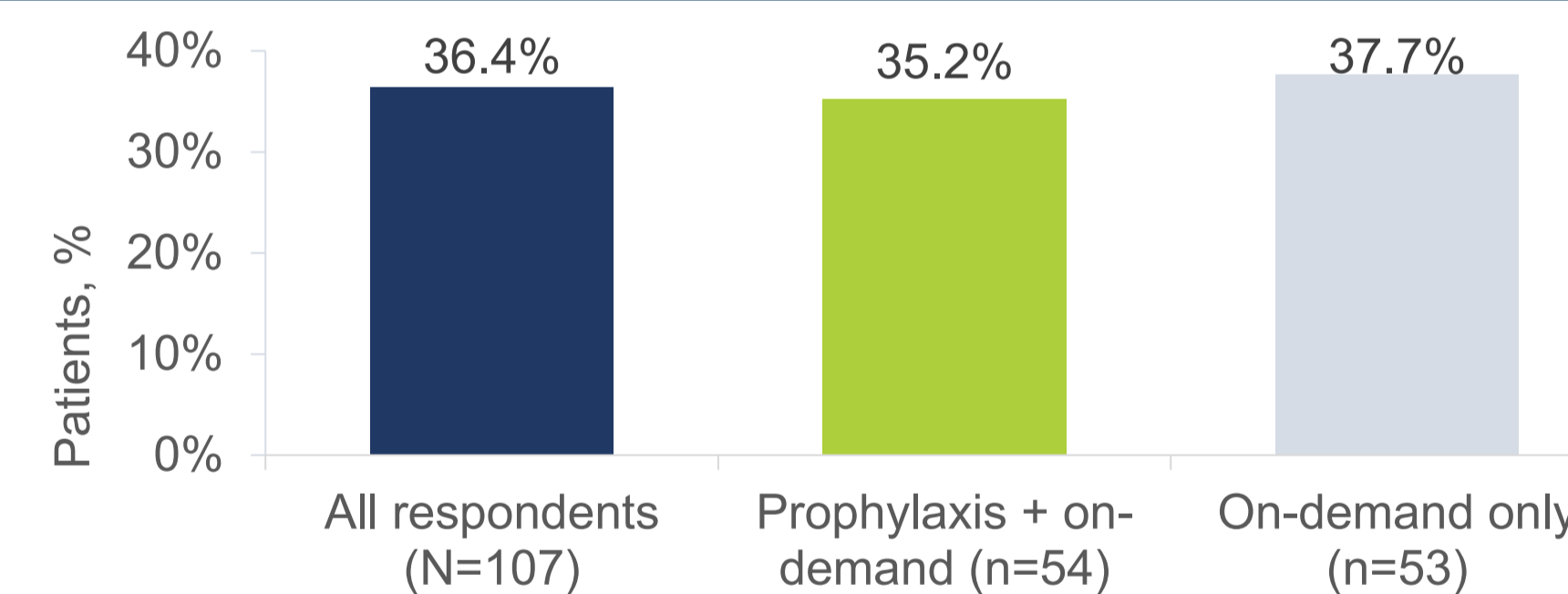
- Use of parenteral on-demand treatment impacted school and work (choice of and day-to-day), especially for those aged <25 years (Table 3)

Table 3. Reported impacts on daily living from on-demand HAE attack treatment

Does your on-demand HAE treatment impact each of the following? (% "Yes")	Total (n=107)	Prophylaxis + on-demand (n=54)	On-demand only (n=53)	Age <25 years	Age <40 years
School	29.9	37.0	22.6	57.1	32.1
Work (day to day work)	57.0	53.7	60.4	71.4	64.3
Work (choice of work)	53.3	51.9	54.7	57.1	51.8
Sports (participation in sports)	50.5	48.1	52.8	50.0	46.4
Travel (choice of destination)	60.7	57.4	64.2	57.1	62.5
Social activities (participation in social activities)	57.0	53.7	60.4	57.1	55.4

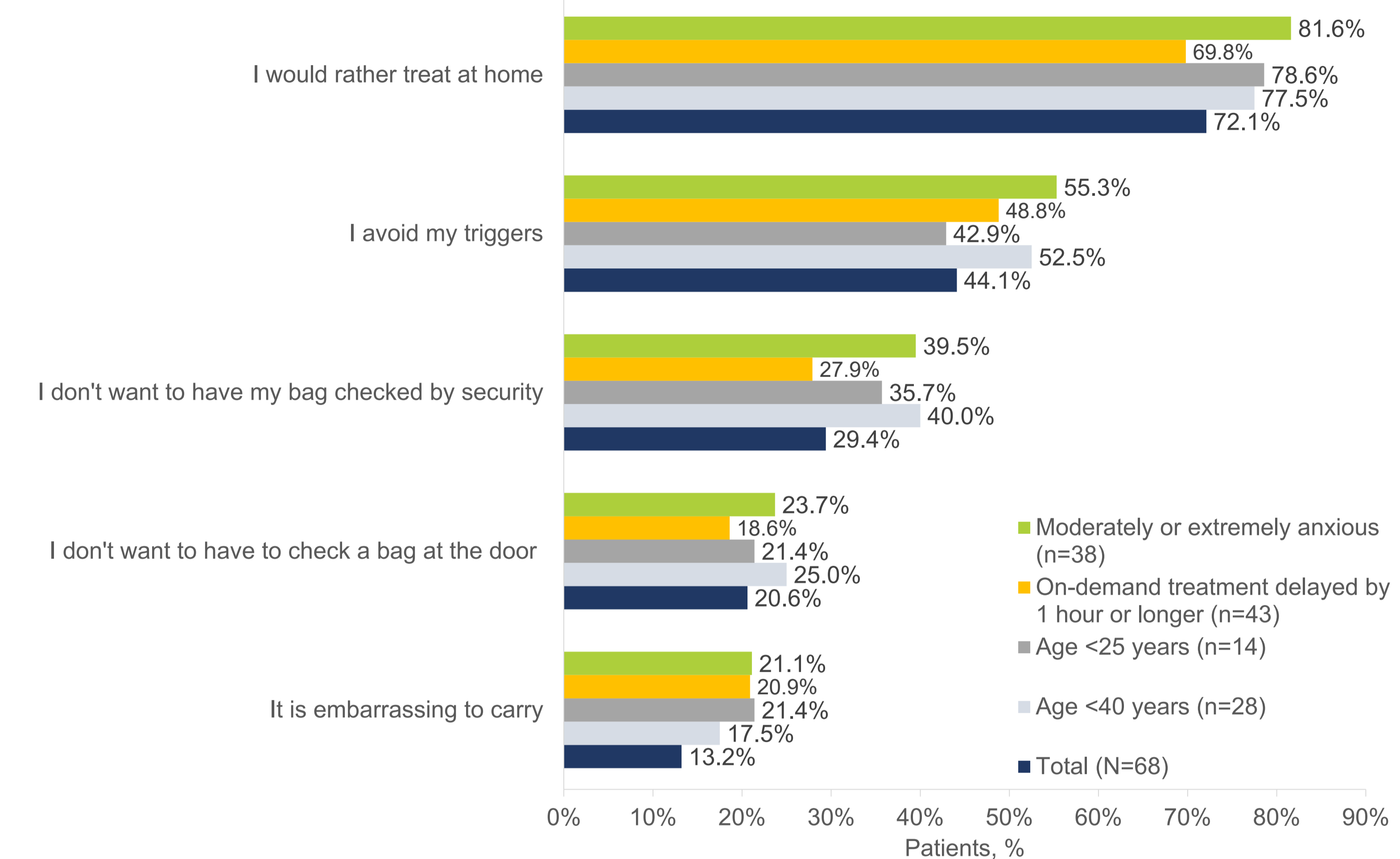
- Overall, only 36.4% reported that they always carry their HAE on-demand treatment when they are away from home (Figure 1)

Figure 1. Proportion of respondents that always carry their HAE on-demand treatment when they are away from home, as part of day-to-day life



- 44.1% of all respondents reported adjusting their daily lives to avoid triggers, rather than carrying on-demand treatment when away from home (Figure 2)
- Reasons for not taking on-demand treatment with them included: 'to avoid having a bag checked by security' (29.4%) and 'don't want to check a bag at the door' (20.6%)
- Of those not taking their on-demand treatment with them (n=68), people feeling more anxious about on-demand treatment and those aged <25 or <40 years more frequently mentioned 'being embarrassed' and 'avoiding triggers and situations where treatment may be discovered by others' as reasons for doing so
- 'Embarrassment' was a reason for not carrying their treatment with them among the 20.9% of those who delayed treatment by ≥1 hour

Figure 2. Reasons given for not carrying on-demand treatment at all times, by those that do not always carry (N=68)



Survey participants who indicated that they do not always carry an HAE on-demand treatment (n=68) were asked to select from a list of reasons they do not take on-demand treatment when away from home

Conclusions

- Results highlight how managing current parenteral on-demand HAE treatment has a range of negative impacts on QoL of people with HAE
- Parenteral on-demand treatments cause anxiety and negatively impact work/school life, especially for those aged <25 years
- To reduce the burden of managing their on-demand treatment, people with HAE often feel the need to make adjustments to their daily lives (eg, avoiding triggers and situations where their on-demand treatment may be discovered by others)
- Embarrassment regarding carrying on-demand treatment was given among the reasons why people with HAE may delay administration of on-demand treatment of an attack by an hour or longer

Presented at:

American Academy of Allergy, Asthma & Immunology (AAAAI) Annual Meeting - February 23-26, 2024, Washington, DC

To view this poster after the presentation, visit KalVista Virtual Booth (<https://medical.kalvista.com/>).

