

# Impact of Injectable HAE On-Demand Treatments on Health-Related Quality of Life: A Patient and Caregiver Interview Study

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## Introduction

- Patients and caregivers face both emotional and logistical burdens with injectable therapies for on-demand treatment of HAE attacks, which can lead to delaying or forgoing treatment<sup>1–3</sup>
- This qualitative study aimed to understand patient and caregiver experiences with injectable on-demand treatments

## Methods

- Patients with HAE and caregivers recruited via patient advocacy organizations, Hereditary Angioedema Association and HAE International
  - Patient eligibility
    - Adults (aged ≥18 years) or adolescents (aged 12–17 years)
    - Self-confirmed diagnosis of HAE Type 1 or Type 2
    - ≥1 HAE attack in the prior 6 months
    - Previous experience using on-demand treatments
  - Caregiver eligibility
    - Age ≥18 years
    - Primary caregiver for a patient (care-recipient)
  - Patient-caregiver eligibility
    - HAE patients
    - Cared for someone with HAE
- Semi-structured, qualitative interviews were conducted
  - Interview guides tailored to respondent subtypes (semi-structured design)
  - Open-ended questions gathered input on use and emotional and physical impacts of injectable on-demand treatment
  - Data analyzed using thematic analysis to identify key themes and subthemes

## Results

### Study participants

- Interview participants (N=25) were based in the UK (n=8) and the US (n=17) (Table 1)
  - 17 patients: 12 adults, including 5 patient-caregivers, and 5 adolescents
  - 8 caregivers: 4 for a child, 4 for an adult

Table 1. Demographic and clinical characteristics

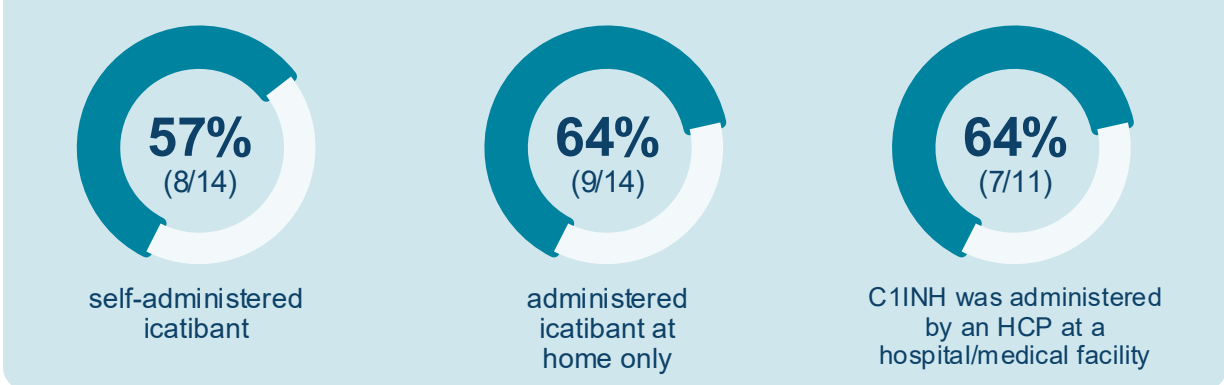
Demographic characteristic	Patients (n=17)	Caregivers (n=8)
<b>Country of residence, n (%)</b>		
US <sup>a</sup>	11 (65)	6 (75)
UK <sup>b</sup>	6 (35)	2 (25)
<b>Age (years), mean (SD) [range]</b>	34 (16.1) [12–60]	43 (7.2) [33–52]
<b>Female sex, n (%)</b>	12 (71)	7 (88)
<b>Clinical characteristics of individuals with HAE<sup>c</sup></b>		
<b>Time since last attack (days), mean (SD) [range]</b>	35 (54.6) [1–180]	71 (86.0) [2–270]
<b>Location of last attack,<sup>d</sup> n (%)</b>		
Abdomen	9 (53)	3 (38)
Extremities/ limbs	5 (29)	4 (50)
Face	2 (12)	2 (25)
Other	1 (6)	0 (0)
<b>Severity of last attack, n (%)</b>		
Mild	4 (24)	2 (25)
Moderate	7 (41)	4 (50)
Severe	6 (35)	2 (25)
<b>Time since diagnosis (years), mean (SD) [range]</b>	21 (15.2) [3–47]	10 (9.4) [5–31]
<b>LTP use,<sup>e</sup> n (%)</b>	14 (82)	6 (75)

<sup>a</sup>From the US there were 11 patients: 7 adults, including 4 patient-caregivers, and 4 adolescents; and 6 caregivers: 3 of a child and 3 of an adult. <sup>b</sup>From the UK there were 6 patients: 5 adults, including 1 patient-caregiver, and 1 adolescent; and 2 caregivers: 1 of a child and 1 of an adult. <sup>c</sup>Data are proxy-reported for the care-recipients by caregivers. <sup>d</sup>Categories were not mutually exclusive. <sup>e</sup>14 patients and 6 care-recipients, respectively, used LTP, including lanadelumab-tyo (Takhzyro) n=5, n=3, C1INH SC (Haegarda) n=3 each, berotralstat (Orladeyo) n=3, n=0, and 'other' (n=3, n=1). C1INH: C1 esterase inhibitor; HAE: hereditary angioedema; LTP: long-term prophylactic; SC: subcutaneous.

### Use of approved on-demand treatment

- 11 patients and 3 caregivers reported use of icatibant (SC administration), and 6 patients and 5 caregivers reported use of a C1 esterase inhibitor (C1INH; IV administration) as their primary on-demand treatment

### Treatment administration



### Treatment delay or withholding



- Participants highlighted lack of portability (n=14; 9 patients and 5 caregivers) and logistical challenges (n=19) as important barriers to treating every attack (Figure 1)

Figure 1. Barriers to injectable on-demand treatments<sup>a</sup>

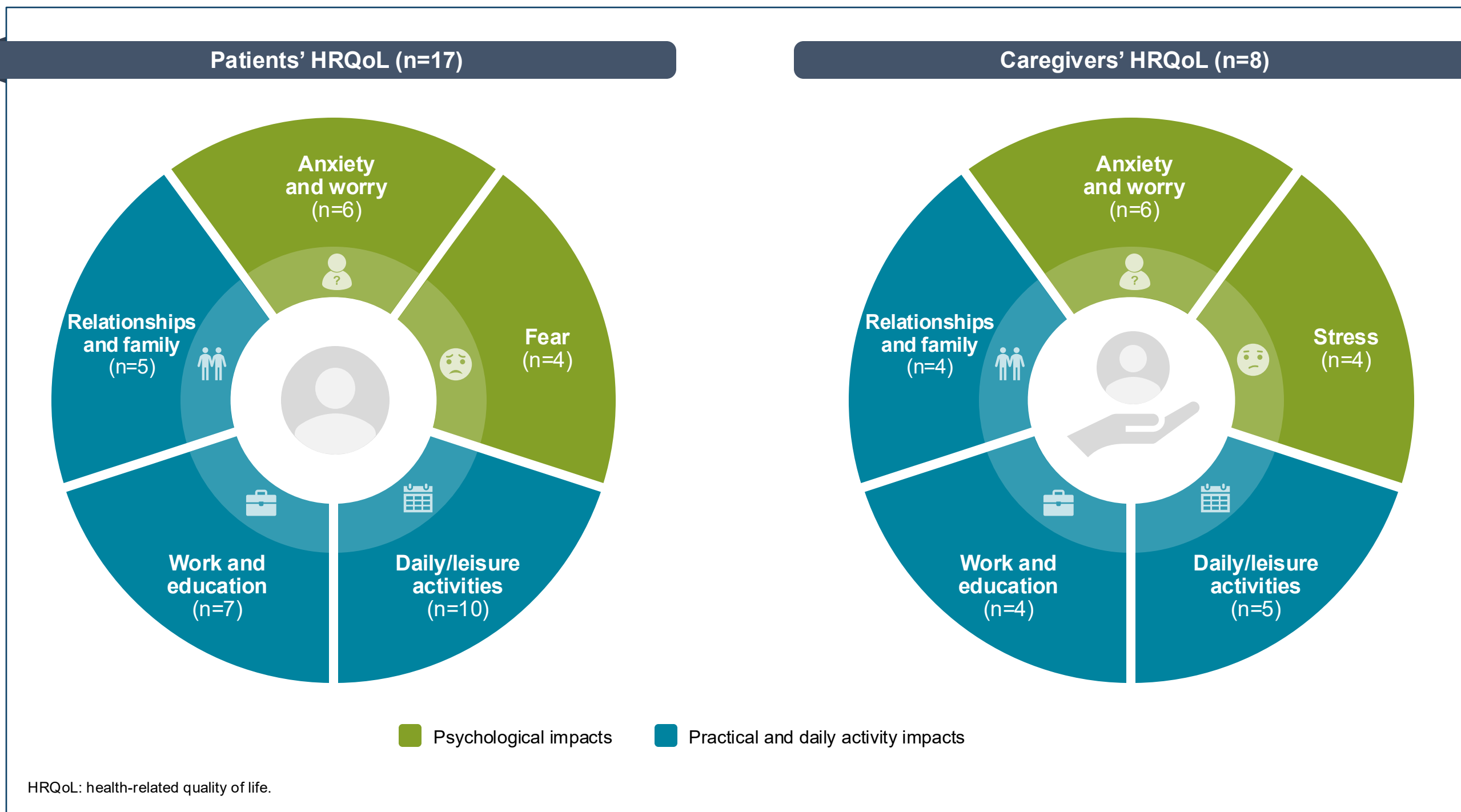


### Patient- and caregiver-reported impacts of injectable on-demand treatments

- Patients expressed fear of needles or pain (Figure 2) (19 participants reported painful administration as a key concern)
- Patients and caregivers both described frustration at having to stop daily and social activities to administer treatments, including work and school days; this impact appeared stronger for adolescents (Figure 2)

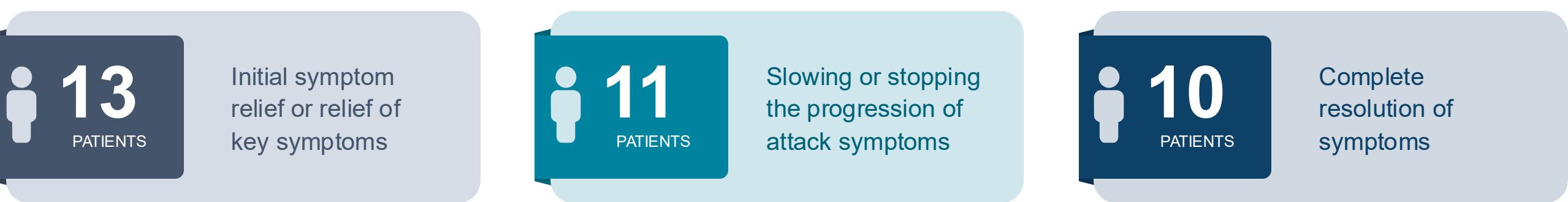
## Results

Figure 2. Impact of injectable on-demand treatment on patients’ and caregivers’ HRQoL



### Defining treatment effectiveness

Figure 3. Participants shared what they considered key aspects of an effective treatment<sup>a</sup>



<sup>a</sup>Participants were asked “What aspects of treatment are important to you?”

## Discussion

- All participants reported delaying on-demand injectable treatment for an attack at least once and 80% reported forgoing treatment for some attacks
- All patients and caregivers described negative effects on HRQoL related to injectable on-demand treatment, often citing pain of injections and logistical barriers to administration
- This study highlights the unmet need for an on-demand treatment that allows for earlier, pain-free administration, is effective at providing symptom relief, while increasing patients’ independence, and ultimately improving HRQoL for both patients and caregivers

### Abbreviations

C1INH: C1 esterase inhibitor; HAE, hereditary angioedema; HCP, healthcare practitioner; HRQoL, health-related quality of life; LTP: long-term prophylactic; IV, intravenous; SC, subcutaneous; UK, United Kingdom; US, United States.

### References

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### Acknowledgments

Medical writing and editorial support for the development of this poster, under the direction of the authors, was provided by Sara Thier, PhD, MPH, and Michele Salemitano, of Ashfield MedComms, an Inizio company, and was funded by KalVista Pharmaceuticals, Inc.

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