

Real-World Impact of Treated Hereditary Angioedema Attacks on Patients' Quality of Life

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Background

- Hereditary angioedema (HAE) is a rare genetic disease associated with unpredictable, painful, and debilitating attacks of tissue swelling in various locations of the body that can be life-threatening depending on the location(s) affected
- Global HAE treatment guidelines recommend that people living with HAE should consider treating all attacks early upon recognizing them in order to reduce the severity and duration of each attack¹⁻³
- Although long-term prophylaxis (LTP) has been shown to reduce attack frequency, it does not eliminate the need for on-demand treatment
- Currently all approved on-demand treatment options require parenteral administration, which can be challenging for certain patients and contributes to notable treatment burden
- We described the relationship of the patient's last treated HAE attack on physical and social components of quality of life (QoL) and the benefit of early treatment

Methods

- The US Hereditary Angioedema Association recruited participants with Type 1 or 2 HAE between April and June 2023; respondents provided consent for their data to be used anonymously or in aggregate
- Participants had to be at least 12 years old and have treated at least 1 HAE attack within the prior 3 months using an approved on-demand therapy
- Recruitment was stratified to include approximately 50% of participants who were taking on-demand treatment only and 50% of those who were receiving LTP plus on-demand treatment at the time of the last treated attack
- Participants completed a 20-minute online survey about their last treated HAE attack
- Physical and social QoL was assessed using a modified version of the Hereditary Angioedema Quality of Life Questionnaire (HAEA-QoLv2)
- Descriptive analyses were conducted

Table 1. Participant Demographics

	Total (n=94)	On-Demand Treatment Only (n=43)	On-Demand Treatment + LTP (n=51)	Adults (n=80)	Adolescents (n=14)
Current Mean Age, Years (SD)	39.4 (17.4)	42.6 (18.7)	36.7 (15.8)	43.8 (15.0)	14.4 (1.5)
Mean Age of Diagnosis, Years (SD)	18 (12.6)	19 (12.7)	17 (12.5)	20 (12.5)	6 (4.1)
Gender					
Male	28%	23%	31%	21%	64%
Female	72%	77%	69%	79%	36%
Race/Ethnicity					
White	87%	91%	84%	89%	79%
Hispanic or Latino	9%	2%	14%	8%	14%
Black/African American	3%	2%	4%	3%	7%
American Indian or Alaskan Native	2%	2%	2%	-	14%
Asian	3%	5%	2%	4%	-
Other	1%	-	2%	1%	-
HAE Type					
Type 1	81%	79%	82%	81%	79%
Type 2	19%	21%	18%	19%	21%

References

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- Busse PJ, Christiansen SC, Riedl MA, et al. *Allergy Clin Immunol Pract*. 2021;9(1):132-150.e3. doi:10.1016/j.jaip.2020.08.046
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Results

Figure 1. On-Demand Therapy Used for Last Treated Attack

On-Demand Therapy	On-Demand Treatment Only (n=43)	On-Demand Treatment + LTP (n=51)	Adults (n=80)	Adolescents (n=14)
Icatibant	63%	66%	77%	NA*
Recombinant C1 Esterase Inhibitor	21%	16%	13%	50%
Plasma Derived C1 Esterase Inhibitor	14%	16%	9%	50%
Ecallantide	2%	2%	3%	0%

*Not approved for patients under 18 years old.

Figure 2. Long-Term Prophylaxis at the Time of Last Treated Attack (n=51)

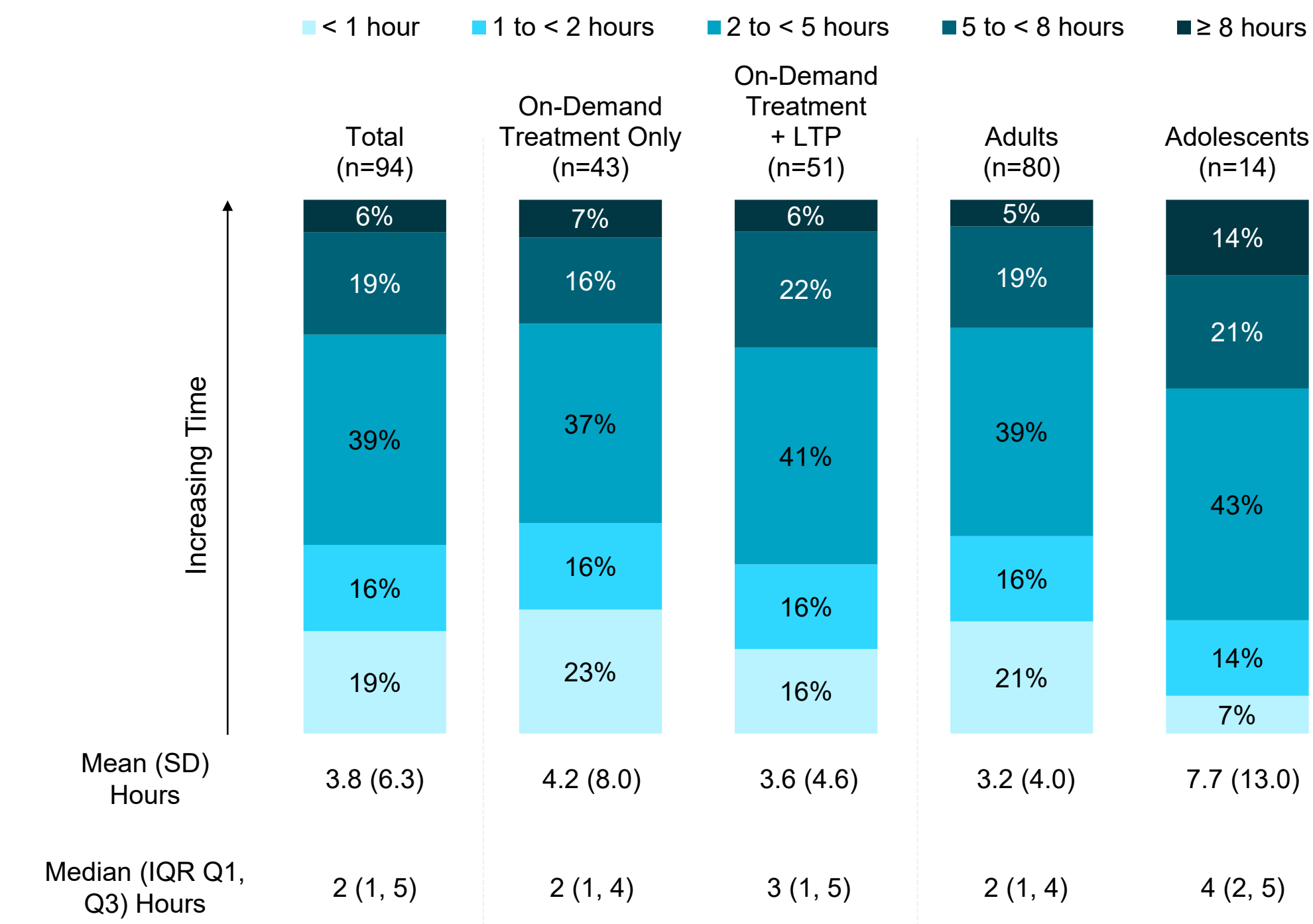
Long-Term Prophylaxis	Adults (n=43)	Adolescents (n=8)
Lanadelumab	57%	25%
Subcutaneous Human C1 Esterase Inhibitor	24%	13%
Bertralstat	14%	38%
Intravenous Human C1 Esterase Inhibitor	6%	25%

Figure 3. Self-reported Attack Severity at the Time of Treatment

Severity	On-Demand Treatment Only (n=43)	On-Demand Treatment + LTP (n=51)	Adults (n=80)	Adolescents (n=14)
Mild	28%	29%	33%	7%
Moderate	63%	49%	56%	50%
Severe	7%	18%	9%	36%
Very severe	2%	4%	3%	7%

- 55% of participants waited until at least moderate severity to treat their attack
- Adolescents were most likely to delay treatment until reaching moderate severity

Figure 4. Time from Attack Onset to On-Demand Treatment



- Median (interquartile range) time from attack onset to on-demand treatment was 2 hours (1-5 hours), with 19% of participants treating in <1 hour
- Adolescents were most likely to delay treatment beyond 1 hour with a median time to treatment of 4 hours

Figure 6. HAEA-QoLv2: Social Outcomes

Statement	On-Demand Treatment Only (n=43)	On-Demand Treatment + LTP (n=51)	Adults (n=80)	Adolescents (n=14)	Time to Initial Treatment					
					< 1 hour (n=18)	1 to < 2 hours (n=15)	2 to < 5 hours (n=37)	5 hours to < 8 hours (n=18)	≥ 8 hours (n=6)	
I felt like a burden to the people around me because I needed help treating the HAE attack	39%	44%	35%	38%	50%	28%	40%	46%	39%	33%
My HAE attack made me feel socially isolated	37%	33%	41%	36%	43%	28%	27%	35%	61%	33%
My HAE attack caused strain with my family	26%	26%	26%	28%	14%	17%	33%	27%	22%	33%
I felt embarrassed when I treated my last HAE attack	23%	19%	28%	19%	50%	11%	33%	24%	28%	17%
My HAE attack caused strain with my colleagues or coworkers	22%	16%	28%	24%	14%	17%	47%	22%	17%	--

- Thirty-seven (39%) participants felt like a burden to people around them because they needed help treating their HAE attacks
- Thirty-five (37%) participants felt social isolation due to HAE attack (28% if treated <1 hour)
- Fewer participants reported negative social outcomes if they had treated their attacks in <1 hour

Conclusions

- These results indicate that the majority of participants' physical and social QoL was substantially affected by their HAE attacks, regardless of being on LTP
- Early treatment of attacks (less than 1 hour) was associated with less negative impact on energy, sleep, activity, and social outcomes
- Taken together, these results highlight the need for education centered on prompt attack intervention

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