

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 both 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 (46% n=43)	On-Demand Treatment + LTP (54% n=51)	Adults (85% n=80)	Adolescents (15% 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

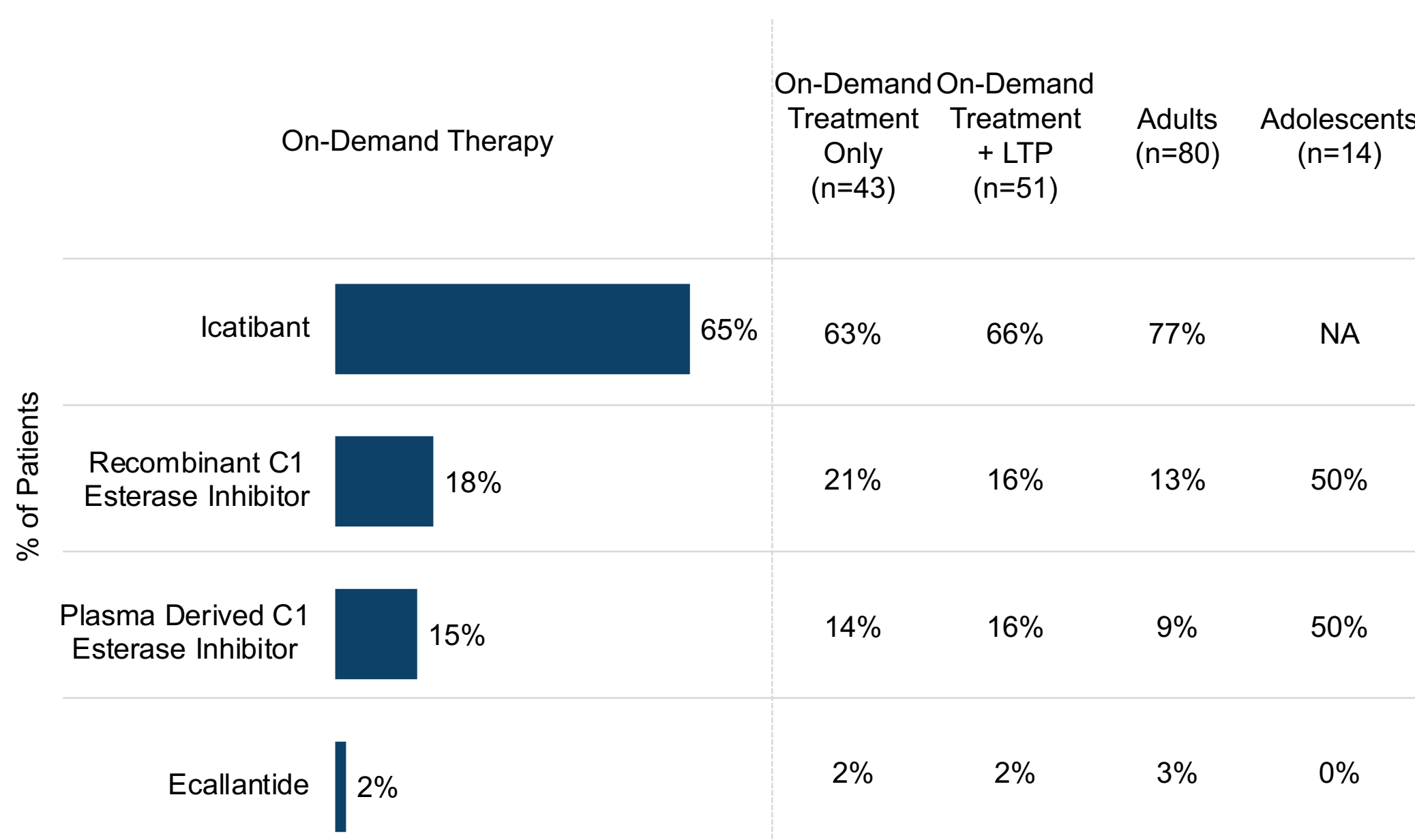


Figure 2. Long-Term Prophylaxis at the Time of Last Treated Attack (n=51)

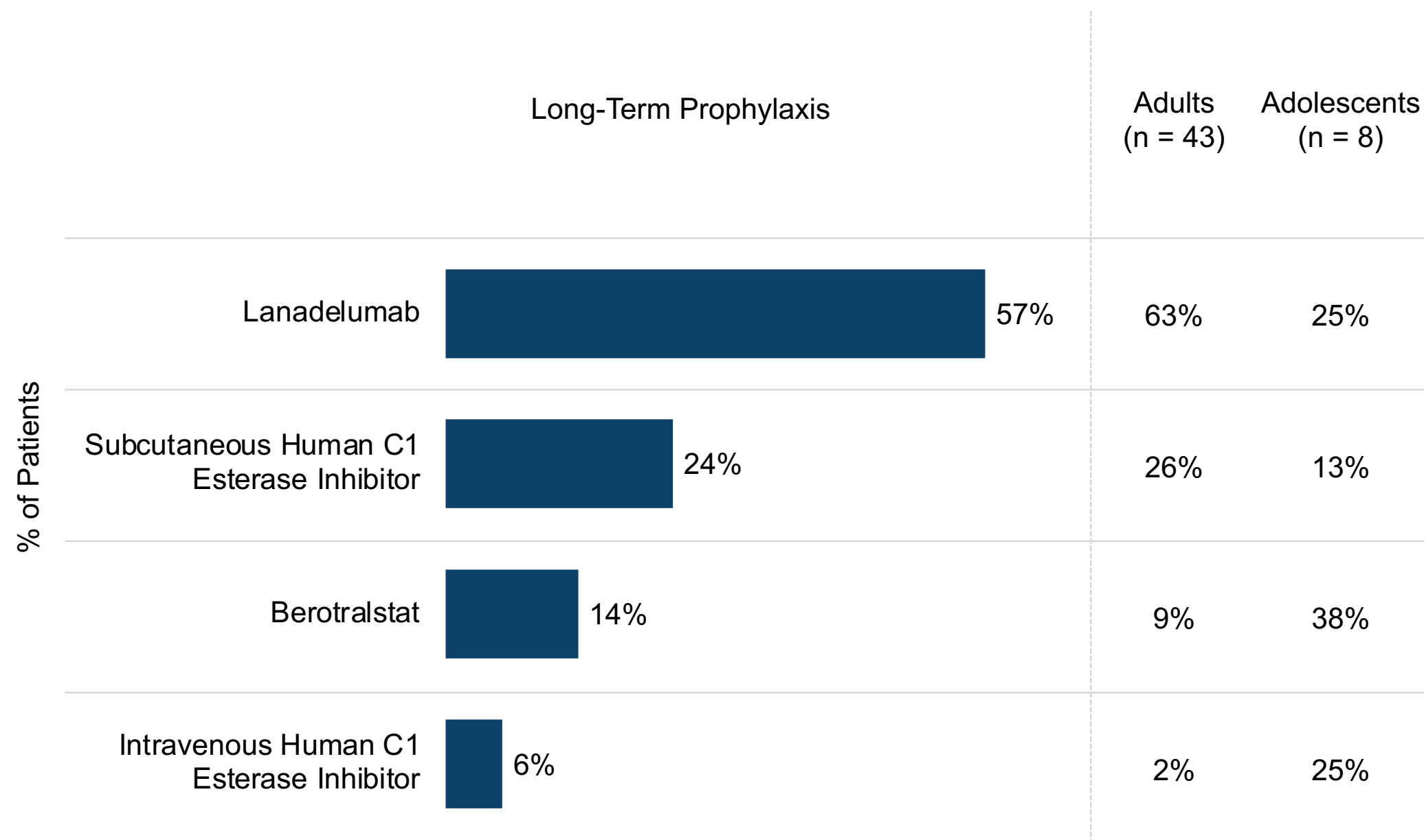
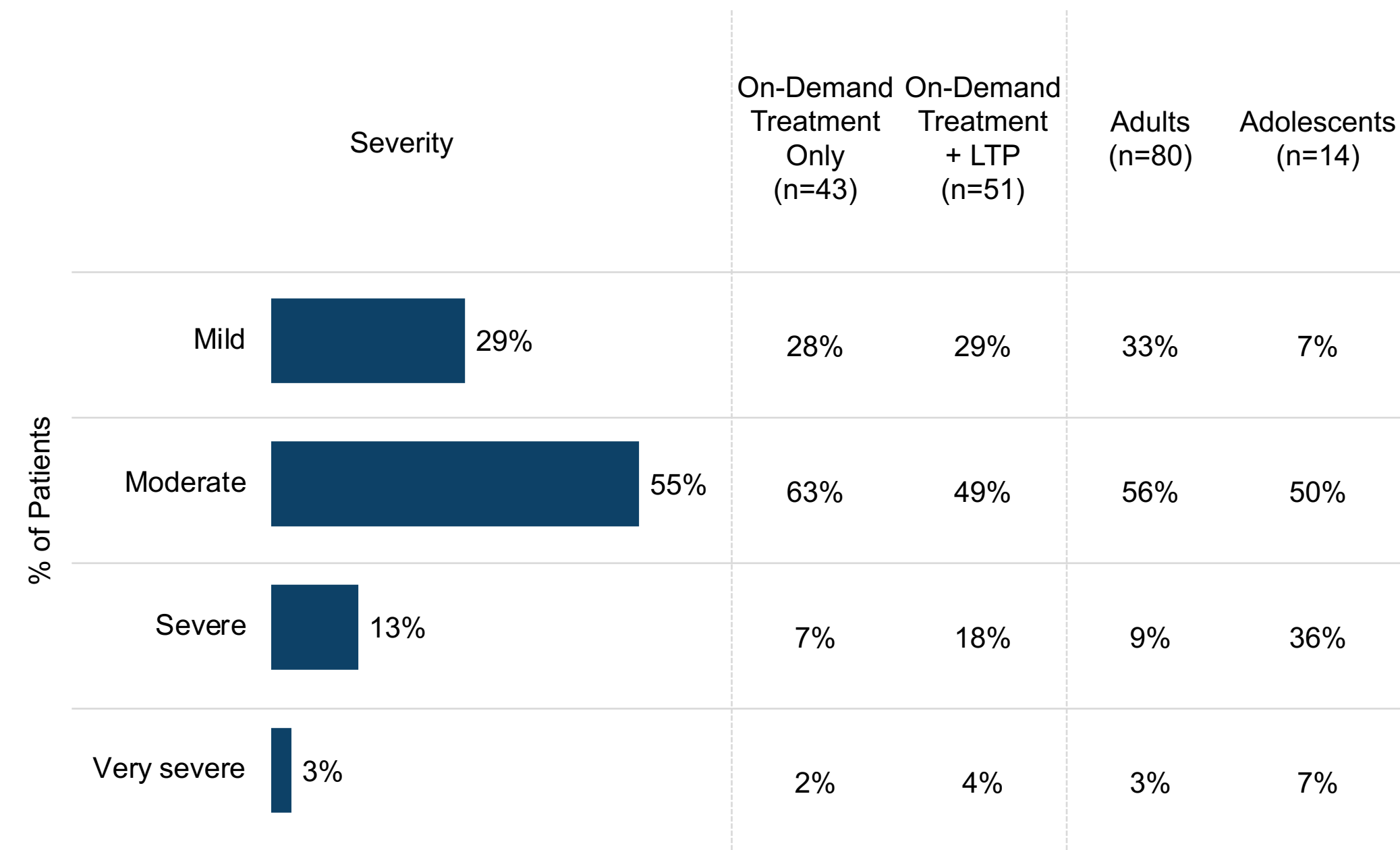
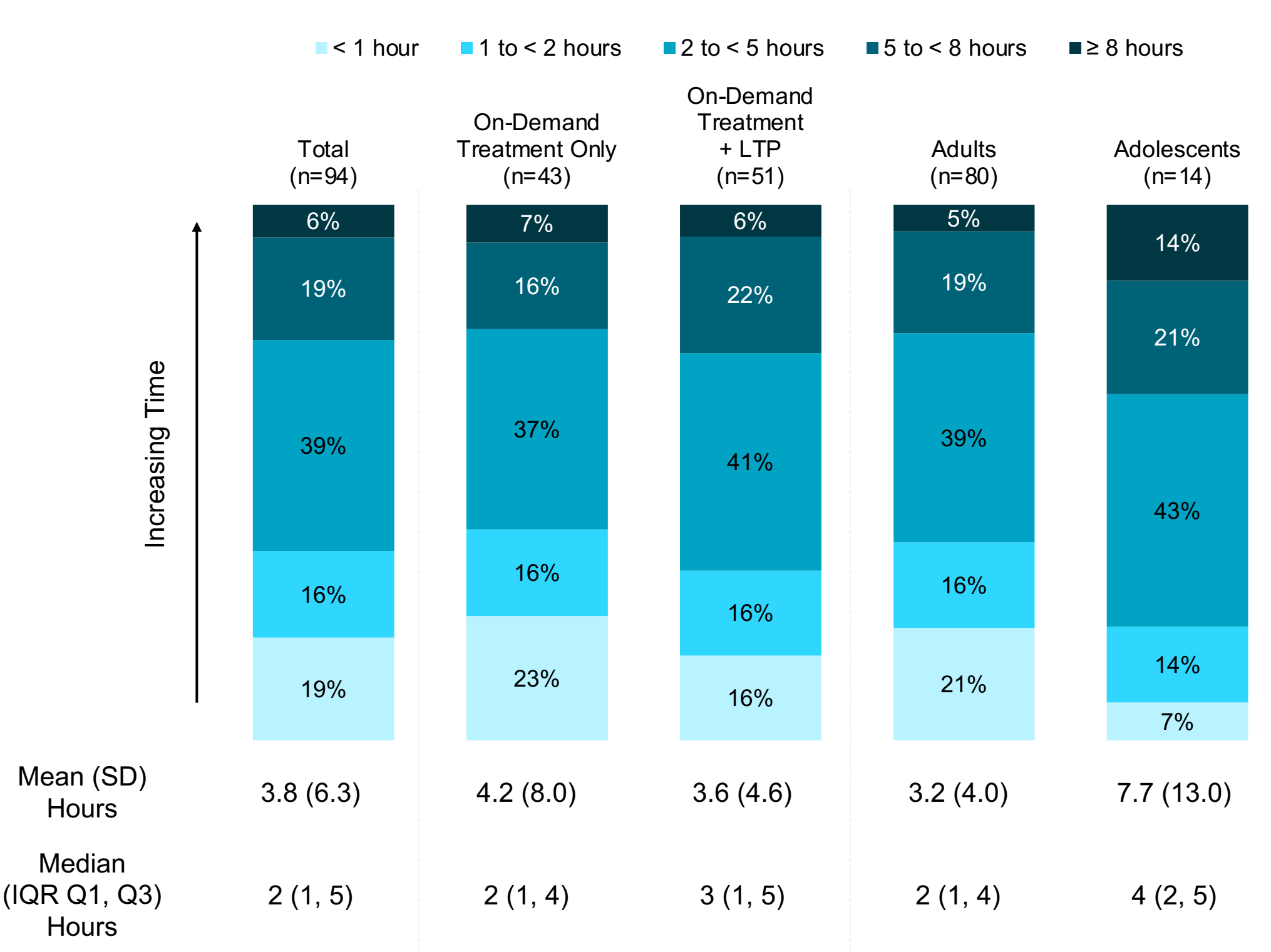


Figure 3. Self-Reported Attack Severity at the Time of Treatment



- 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



- 55% of participants waited until at least moderate severity to treat their attack
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Figure 6. HAEA-QoLv2: Social Outcomes

		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

Acknowledgments

The authors wish to thank Jason Allaire, PhD, of Generativity Health Outcomes Research for his assistance with this poster. Funding for Dr. Allaire was provided by KalVista Pharmaceuticals.

Presented

ISPOR Annual Meeting 2024. May 5-8, in Atlanta, GA
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