

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 (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

- Betschel S, Badiou J, Binkley K, et al. *Allergy, Asthma & Clinical Immunology*. 2019;15(1):72. doi:10.1186/s13223-019-0376-8
- 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
- Maurer M, Magerl M, Betschel S, et al. *Allergy*. 2022;77(7):1961-1990. doi:10.1111/all.15214

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

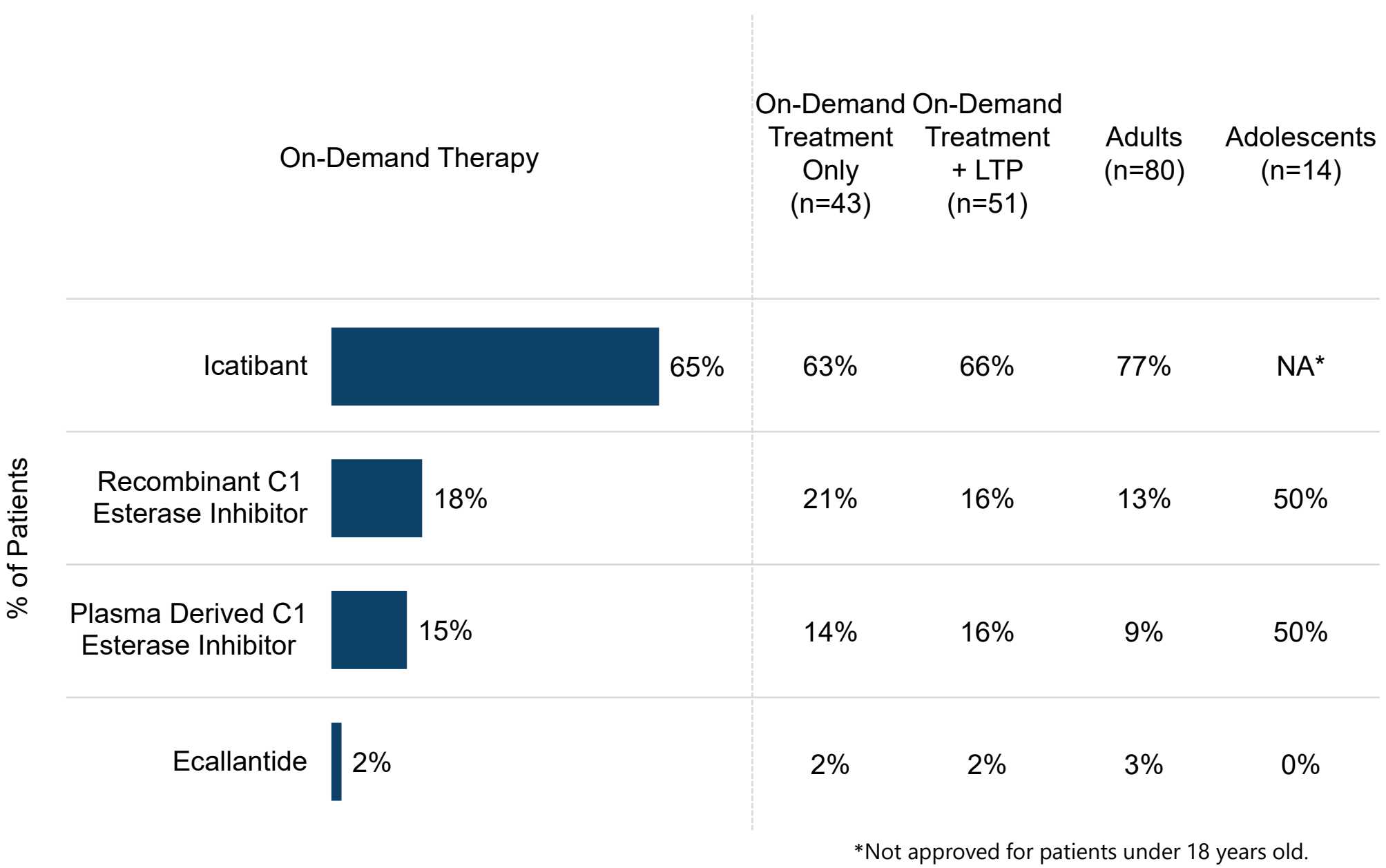


Figure 2. Long-Term Prophylaxis at the Time of Last Treated Attack (n=51)

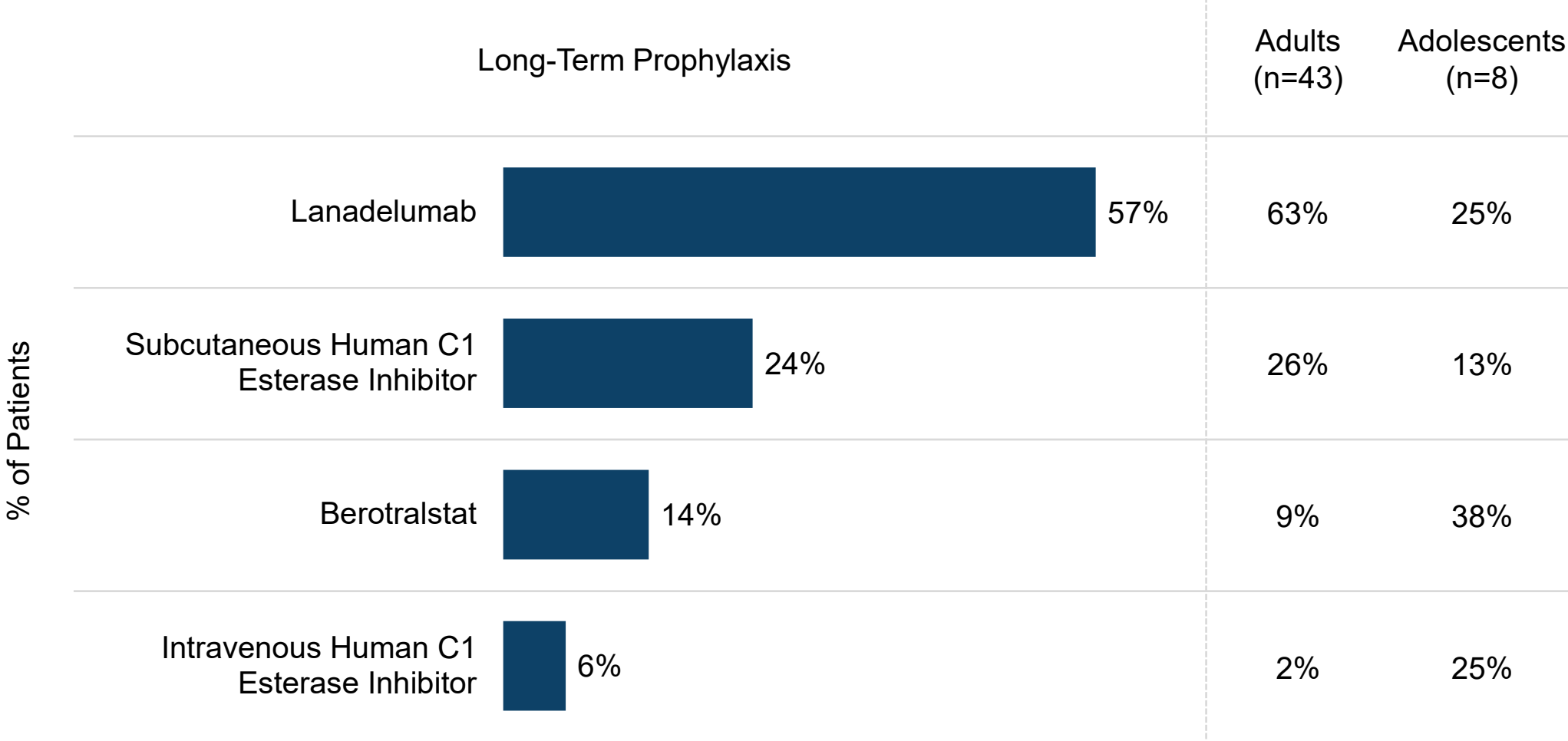
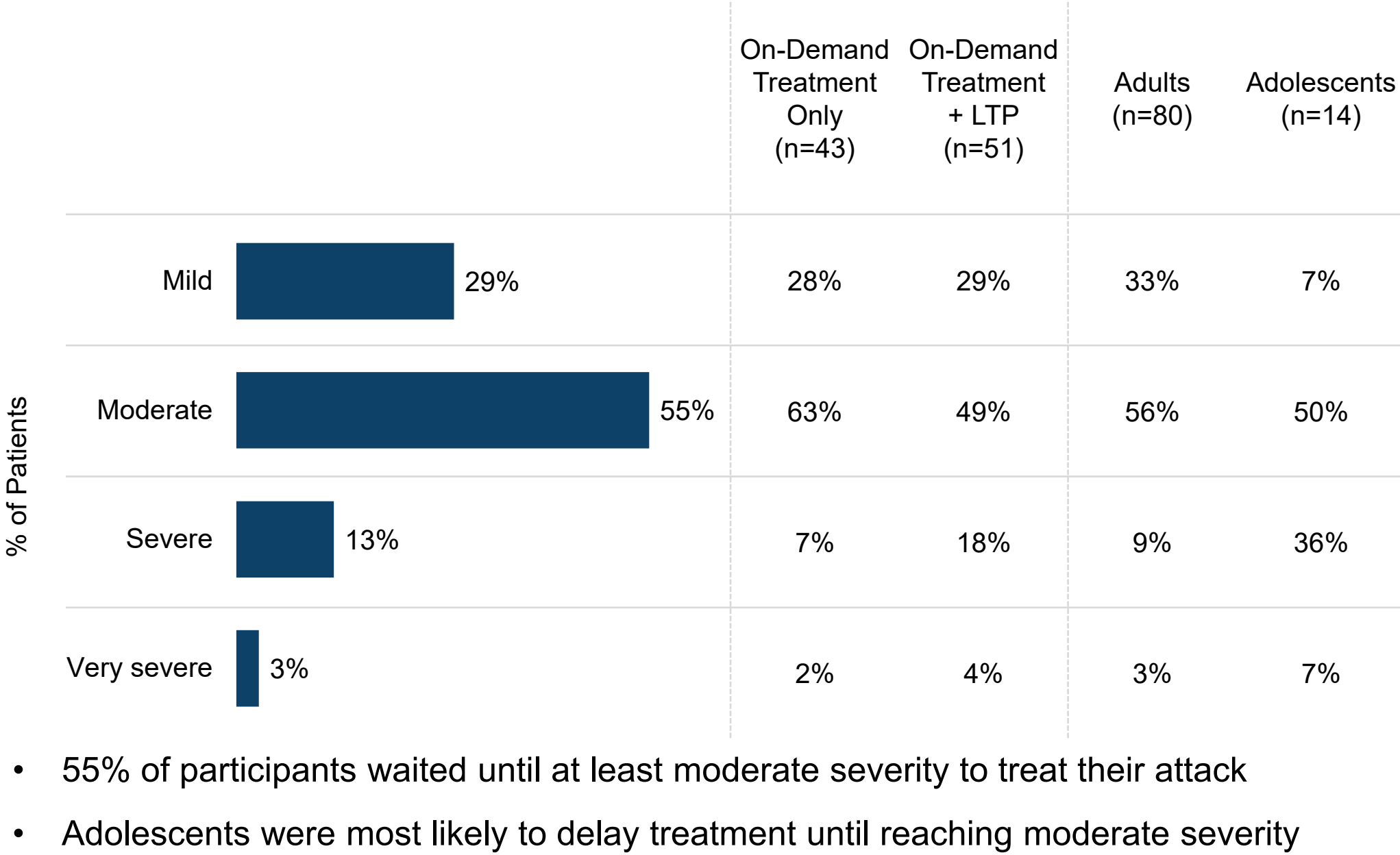


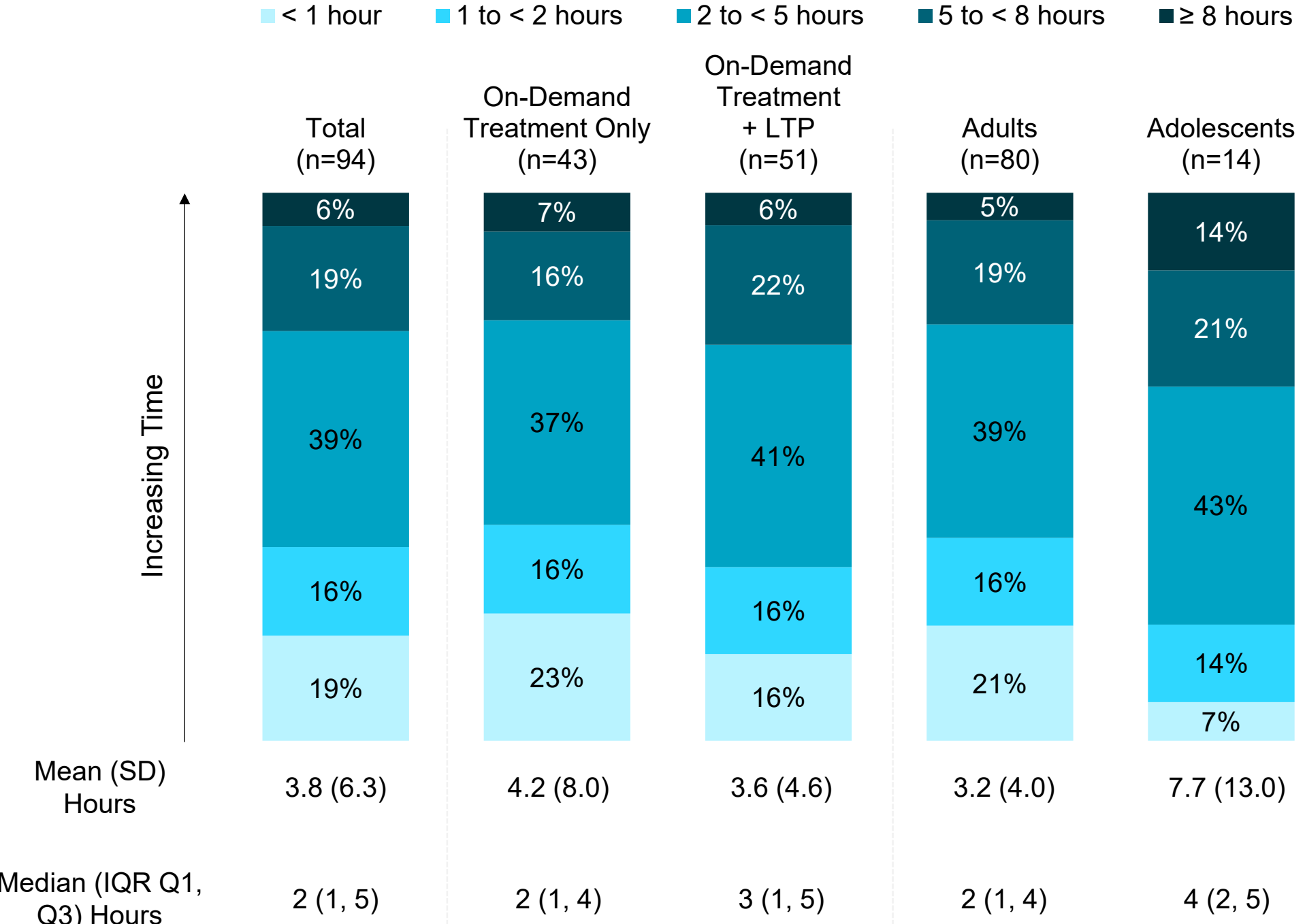
Figure 3. Self-reported Attack Severity at the Time of Treatment



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

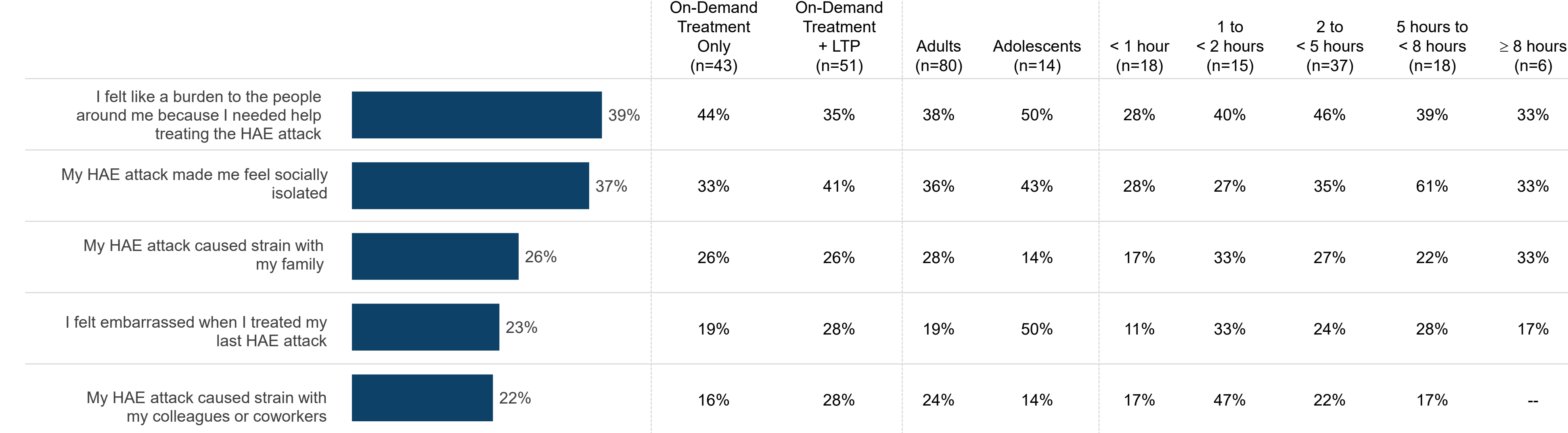
Results

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

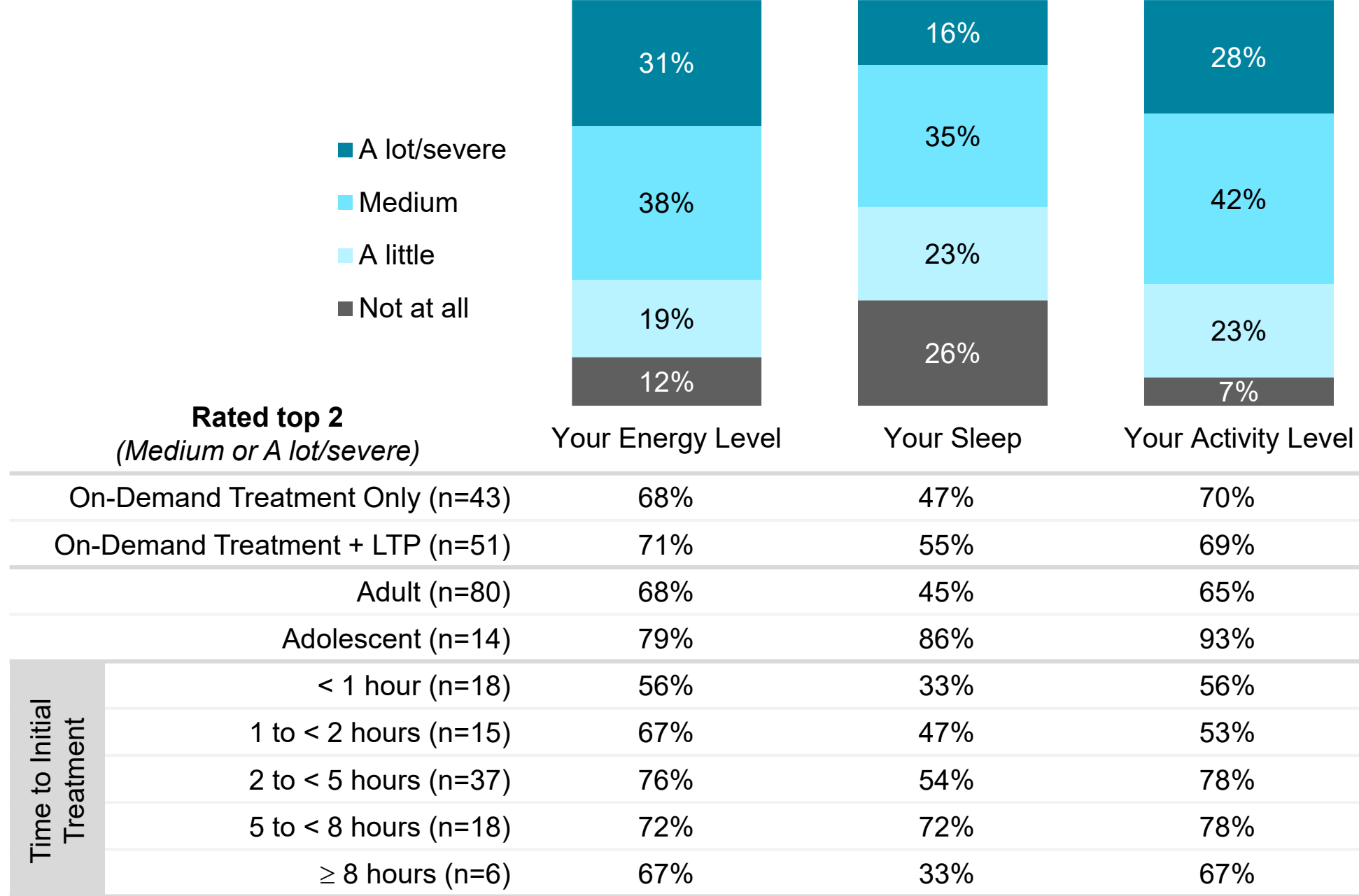


- Thirty-seven (39%) participants felt like a burden to people around them because they needed help treating their HAE attacks
- Thirty-five (37%) participants felt social isolation due to HAE attack (28% if treated <1 hour)
- Fewer participants reported negative social outcomes if they had treated their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

Figure 5. HAEA-QoLv2: Physical Outcomes



- Over 50% of participants reported that their last attack had a medium/severe impact on their energy levels, sleep, and activity levels
 - Participants that treated their attacks in <1 vs ≥5 hours experienced less of an impact on their energy levels, sleep, and activity levels
 - Activity levels were similar in participants receiving prophylaxis and on-demand treatment compared to those receiving on-demand treatment only

Presented

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