

Burden of Untreated Hereditary Angioedema Attacks and its Impact on Social, Mental, and Physical Health

Cristine Radojicic¹, Paula Busse², Maeve O'Connor³, Julie Ulloa⁴, Sherry Danese⁴, Vibha Desai⁵, Tomas Andriotti⁵, Paul Audhya⁵, Sandra Christiansen⁶

¹Duke University School of Medicine, Durham, NC, USA; ²The Mount Sinai Hospital, New York, NY, USA; ³Allergy, Asthma, & Immunology Relief of Charlotte, Charlotte, NC, USA; ⁴Outcomes Insights, Agoura Hills, CA, USA; ⁵KalVista Pharmaceuticals, Cambridge, MA, USA; ⁶University of California San Diego, La Jolla, CA, USA

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 morbidity and mortality¹⁻³
- Despite availability of on-demand therapies, patients do not universally treat attacks⁴

Objective

- We examined the impact of the patients' last untreated attack on social, mental, and physical health

Methods

- The US Hereditary Angioedema Association recruited participants with Type 1 or 2 HAE between April and June 2023
 - Recruitment was stratified to include approximately 50% of participants taking on-demand only and 50% receiving non-androgen long-term prophylaxis (LTP) plus on-demand, at the time of their last treated attack
- Participants completed a 20-minute, self-reported, online survey that inquired about their last untreated HAE attack
- Participants had to be at least 18 years old and had at least 1 untreated attack in the past 3 months
- Physical and social QoL was assessed using a modified version of the Hereditary Angioedema Quality of Life Questionnaire (HAEA-QoLv2)
 - Physical impact of HAE (energy level, sleep, and activity level)
 - Range from 1 (not at all) to 4 (severe/very severe)
 - Social impact of HAE (ex. felt embarrassed, felt socially isolated)
 - Range from 1 (strongly disagree) to 5 (strongly agree)
- EuroQoL Five-Dimensions Five-Levels (EQ-5D-5L), a self-report survey, was used to assess physical and mental QoL "today" (i.e., current QoL) and at the time of the last untreated attack
 - EQ-5D-5L Index Score = QoL composite of items across 5 domains: mobility, self-care, usual activities, pain/discomfort, and anxiety/depression
 - Range from -0.59 (lowest possible health state) to 1 (best possible health state)
 - Visual Analogue Score (VAS) = Single-item, self-assessment of overall health status
 - Range from 0 ("worst imaginable health state") to 100 ("best imaginable health state")

References

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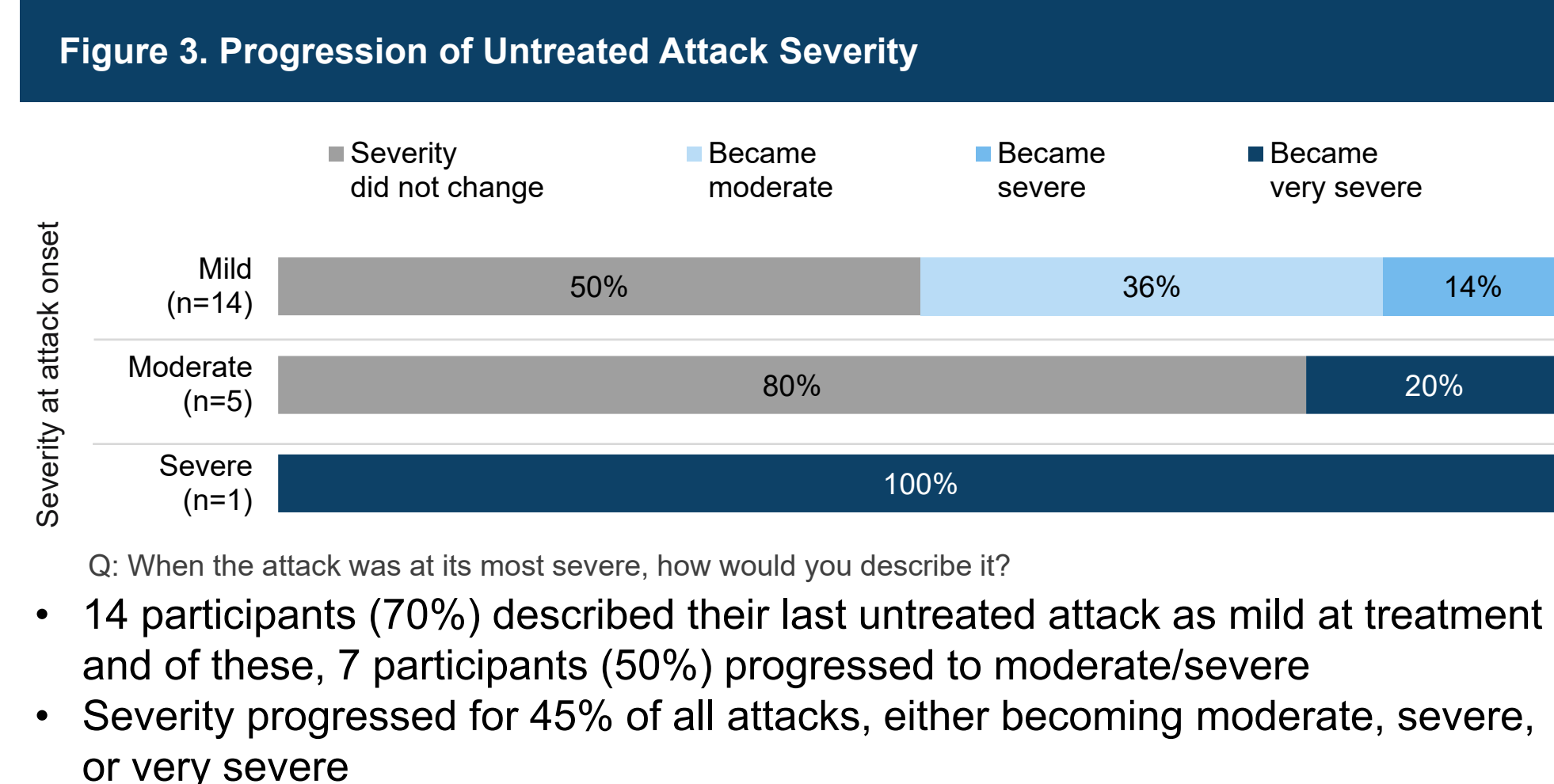
	Total (n=20)	On-Demand Treatment Only (n=9)	On-Demand Treatment + LTP (n=11)
Current Mean Age, Years (SD)	39 (14.6)	45 (14.2)	33 (13.1)
HAE Type			
Type 1	80%	89%	73%
Type 2	20%	11%	27%
Gender			
Female	75%	67%	82%
Race / Ethnicity			
White	87%	89%	79%
Hispanic or Latino	9%	8%	14%
Black/African American	3%	3%	7%
American Indian/Alaskan Native	2%	0%	14%
Asian	3%	4%	0%
Other	1%	1%	0%

- On-demand treatment only participants and on-demand + LTP participants both reported having an average of 10 attacks over the past year
 - On-demand treatment only participants treated 22% of attacks
 - On-demand + LTP participants treated 64% of attacks

On-Demand Therapy	On-demand Treatment Only (n=9)	On-demand Treatment + LTP (n=11)
Icatibant	75%	73%
Plasma Derived C1 Esterase Inhibitor	30%	36%

- 55% reported self-administering on-demand treatment for their attacks

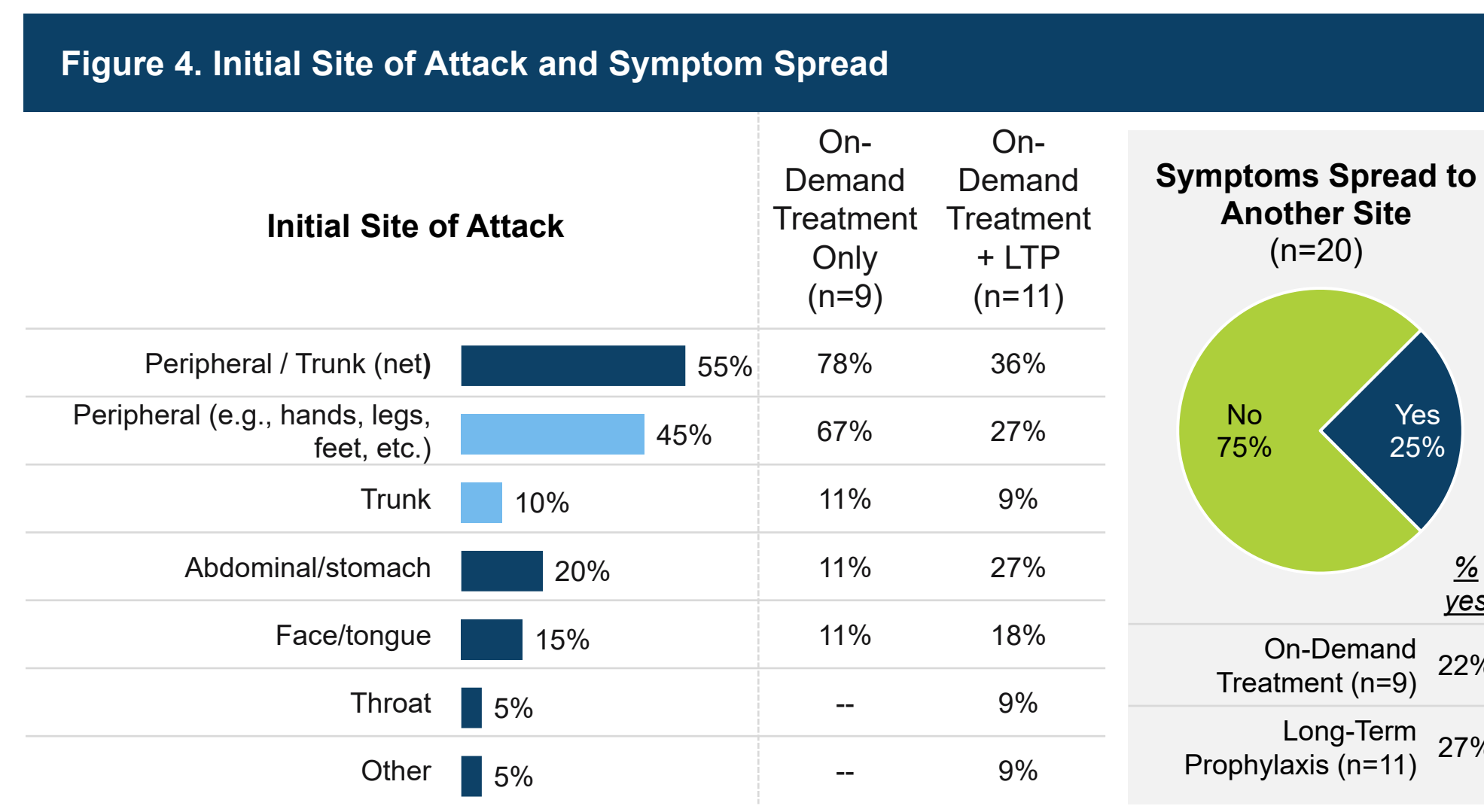
Bertralstat	46%
Lanadelumab	27%
Subcutaneous Human C1 Esterase Inhibitor	18%
Intravenous Human C1 Esterase Inhibitor	9%



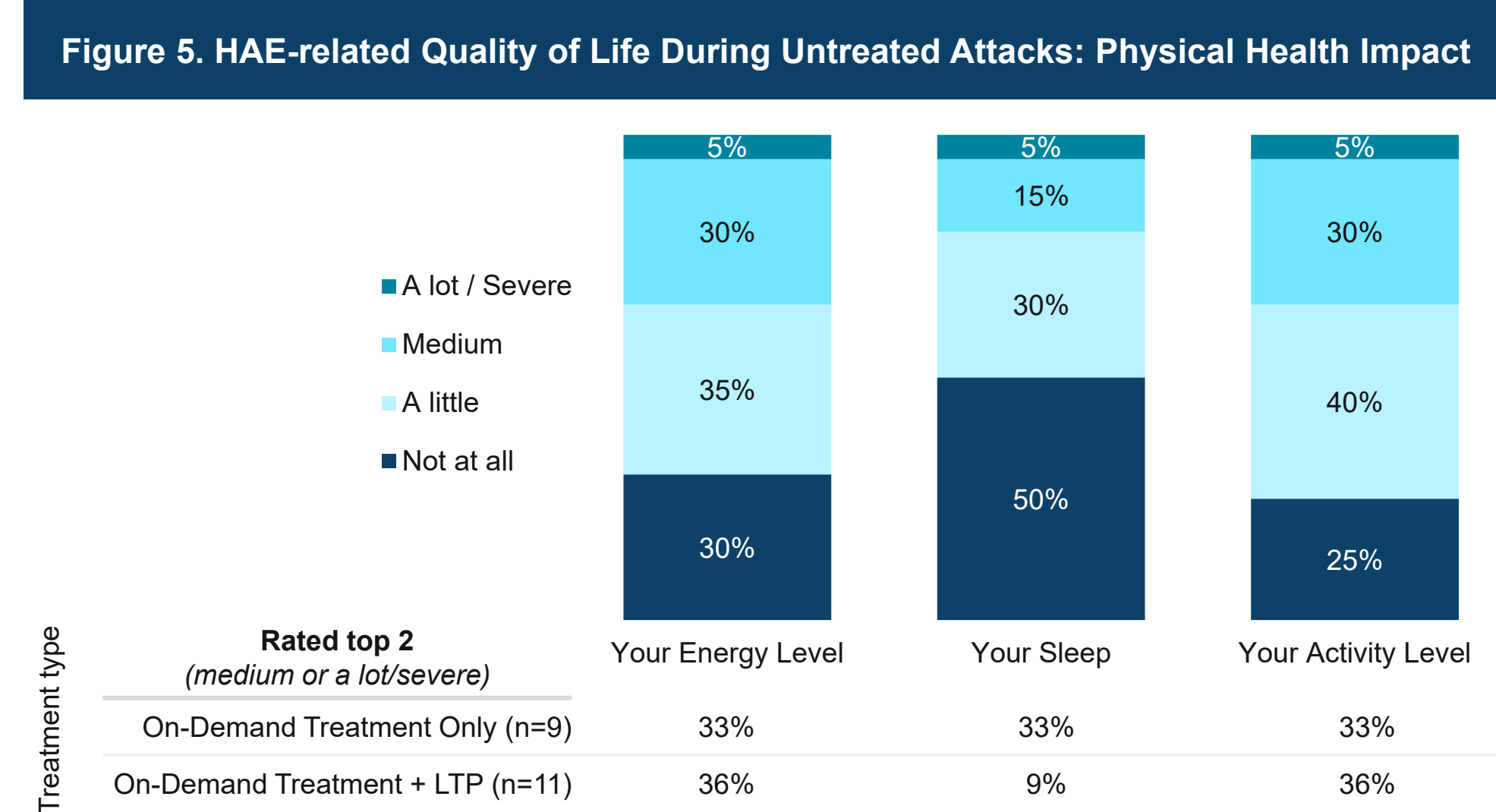
Acknowledgments

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Results



- One in five patients reported that their last untreated attack affected their face/tongue (15%) or throat (5%)
- Five attacks (25%) spread to other locations, including 1 to the larynx and 1 to the face



- At least 50% of participants reported that their last untreated attack impacted their energy levels, sleep, or activity levels at least "a little"

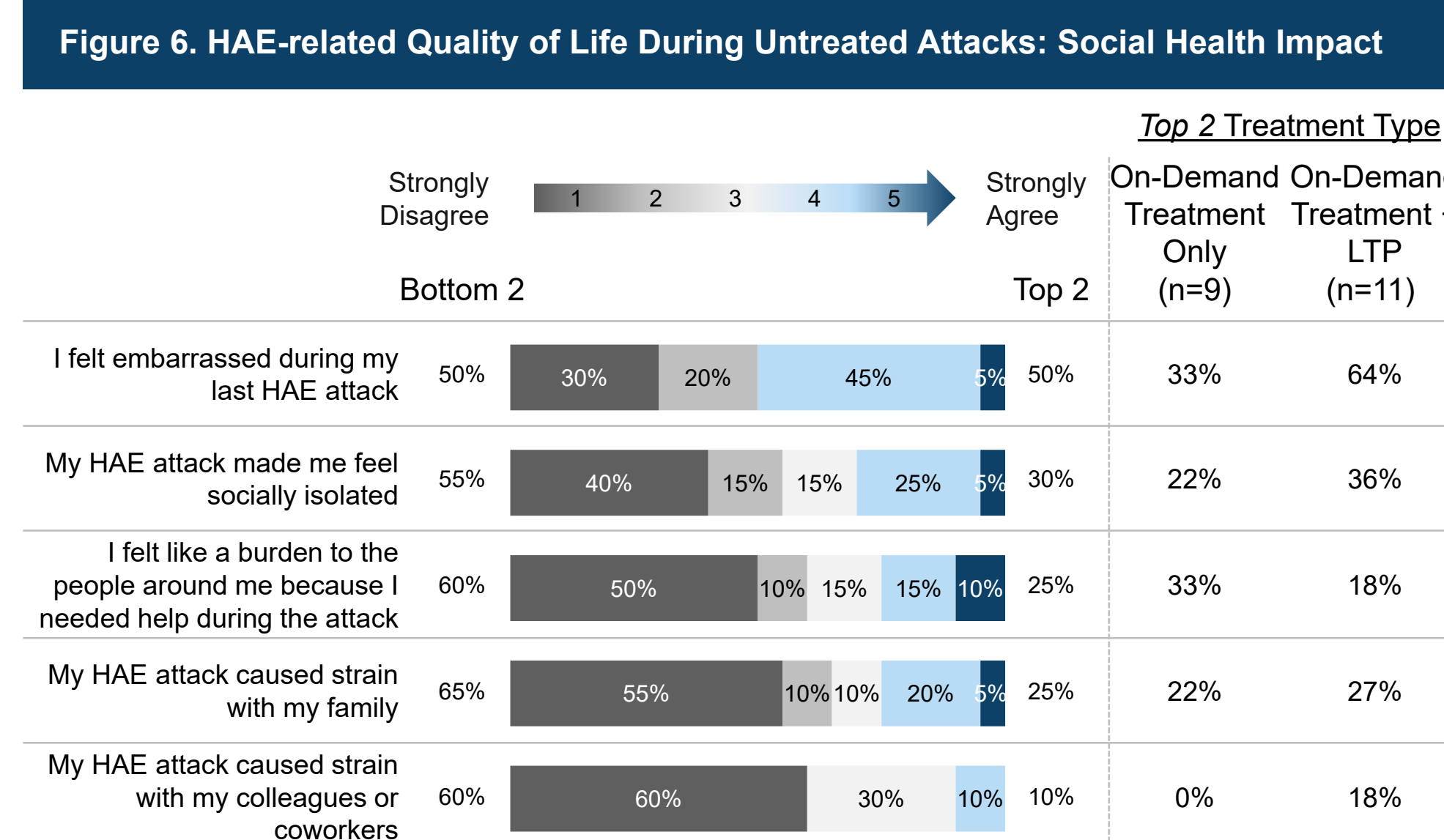
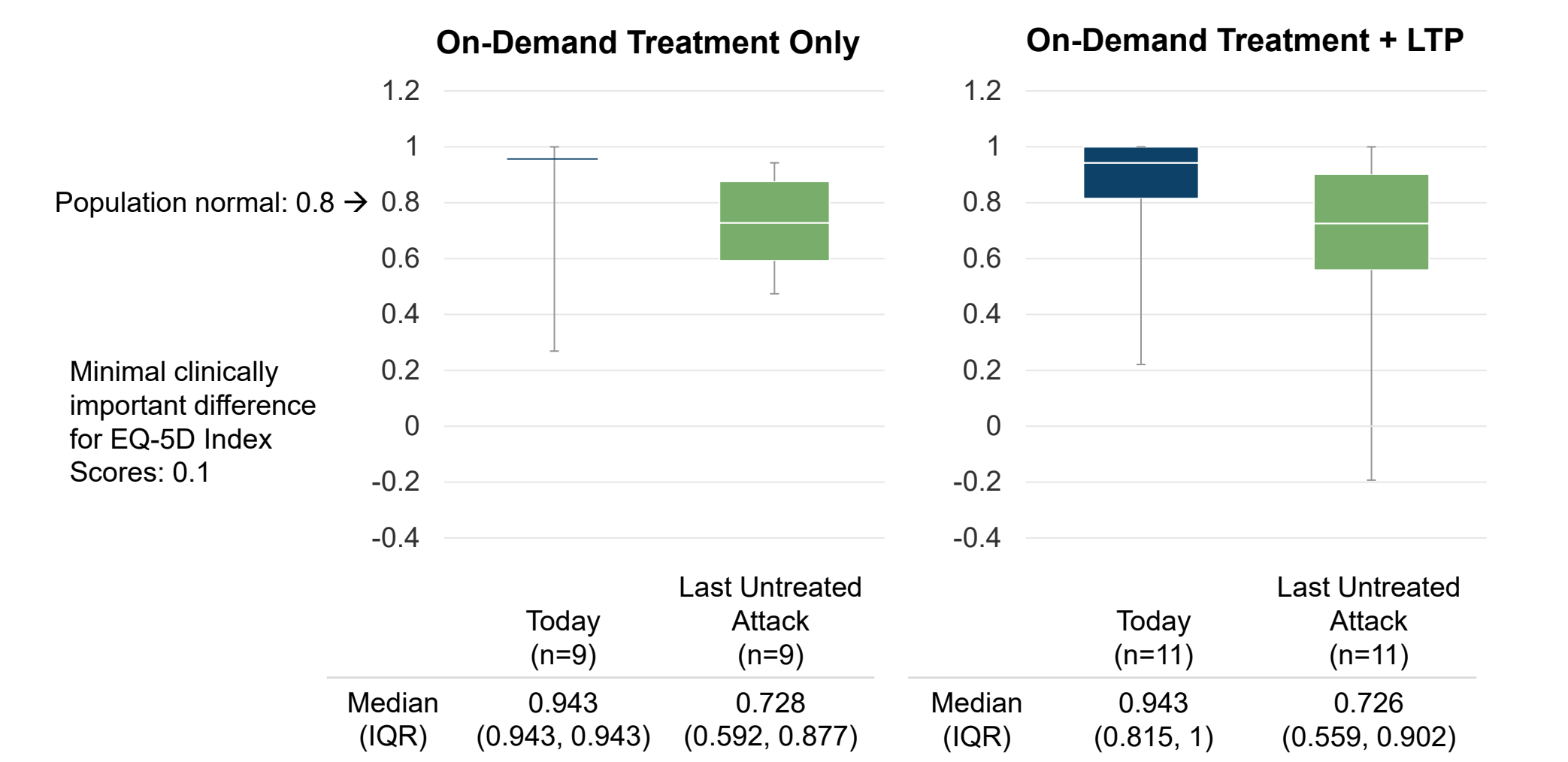
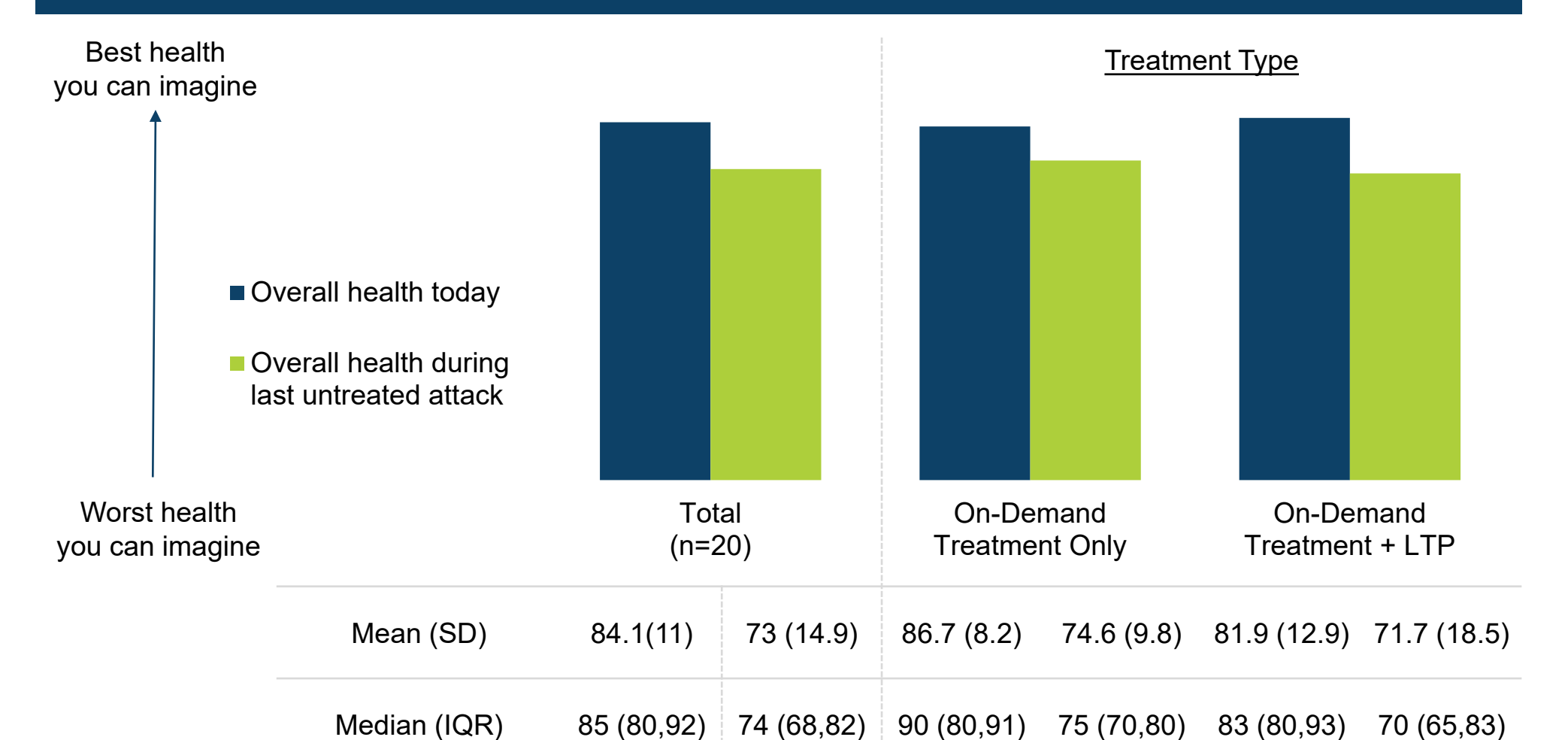


Figure 7. Physical and Mental Quality of Life (EQ-5D Index Scores) Today and During the Last Untreated Attack by Treatment



- QoL index scores decrease as attack severity increased from mild (median 0.736) to moderate (median 0.622)

Figure 8. EQ-5D-5L VAS (General Health) Scores for Current and Last Treated Attack



- General health scores were worse at the time of attack for both treatment groups

Conclusions

- HAE patients receiving on-demand only and those also taking LTP reported that untreated attacks:
 - Often progressed in severity
 - Migrated to other locations, including the larynx
 - Were associated with negative impact on both social and physical health
- Decreased QoL and general health scores were reported during the untreated attacks
- Results emphasize the need for greater education on the implications of not treating HAE attacks and support guidelines that all attacks should be considered for treatment

Presented

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