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# Health-Related Quality of Life and Clinical Characteristics in People Living with Hereditary Angioedema Prescribed Long Term Prophylaxis Alone and On-Demand Treatment Alone

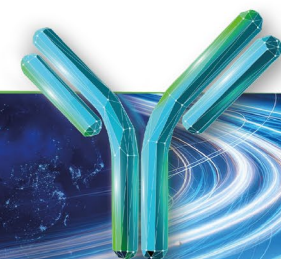
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# Conflict of interest disclosures

**L.B.:** BioCryst, Blueprint, CSL Behring, GSK, KalVista, Novartis, Pharvaris, Takeda; **J.A.:** BioCryst, BioMarin, CSL Behring, Cycle Pharma, KalVista, Pharming, Pharvaris, Takeda; **P.J.B.:** BioCryst, CSL Behring, CVS Pharmacy, Medscape, Novartis, Regeneron, Takeda; **T.C.:** Astria, BioCryst, CSL Behring, KalVista, Novartis, Pharming, Pharvaris, Takeda; is a researcher from the IdiPAZ program for promoting research activities;

**W.R.L.:** AstraZeneca, Astria, BioCryst, BioMarin, CSL Behring, Fresenius-Kabi, GSK, Grifols, Intellia, Ionis, KalVista, Magellan, Optinose, Pharming, Pharvaris, Regeneron, Sanofi, Takeda, Teva; **M.M.:** BioCryst, CSL Behring, Intellia, KalVista, Novartis, Octapharma, Pharming, Pharvaris, Takeda; **M.A.R.:** Astria, BioCryst, BioMarin, Celldex, CSL Behring, Cycle Pharma, Grifols, Intellia, Ionis, KalVista, Novartis, Pharming, Pharvaris, Sanofi-Regeneron, Takeda; **P.F.K.Y.:** Astria, BioCryst, CSL Behring, KalVista, Pharming, Pharvaris, Takeda;

**A.Z.:** BioCryst, CSL Behring, KalVista, Pharming, Takeda; **K.W.-C., G.C.:** employees of Adelphi Real World; **J.M.:** employee of Pharvaris, holds stocks in Pharvaris.

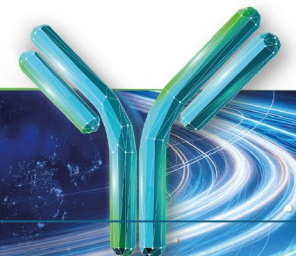
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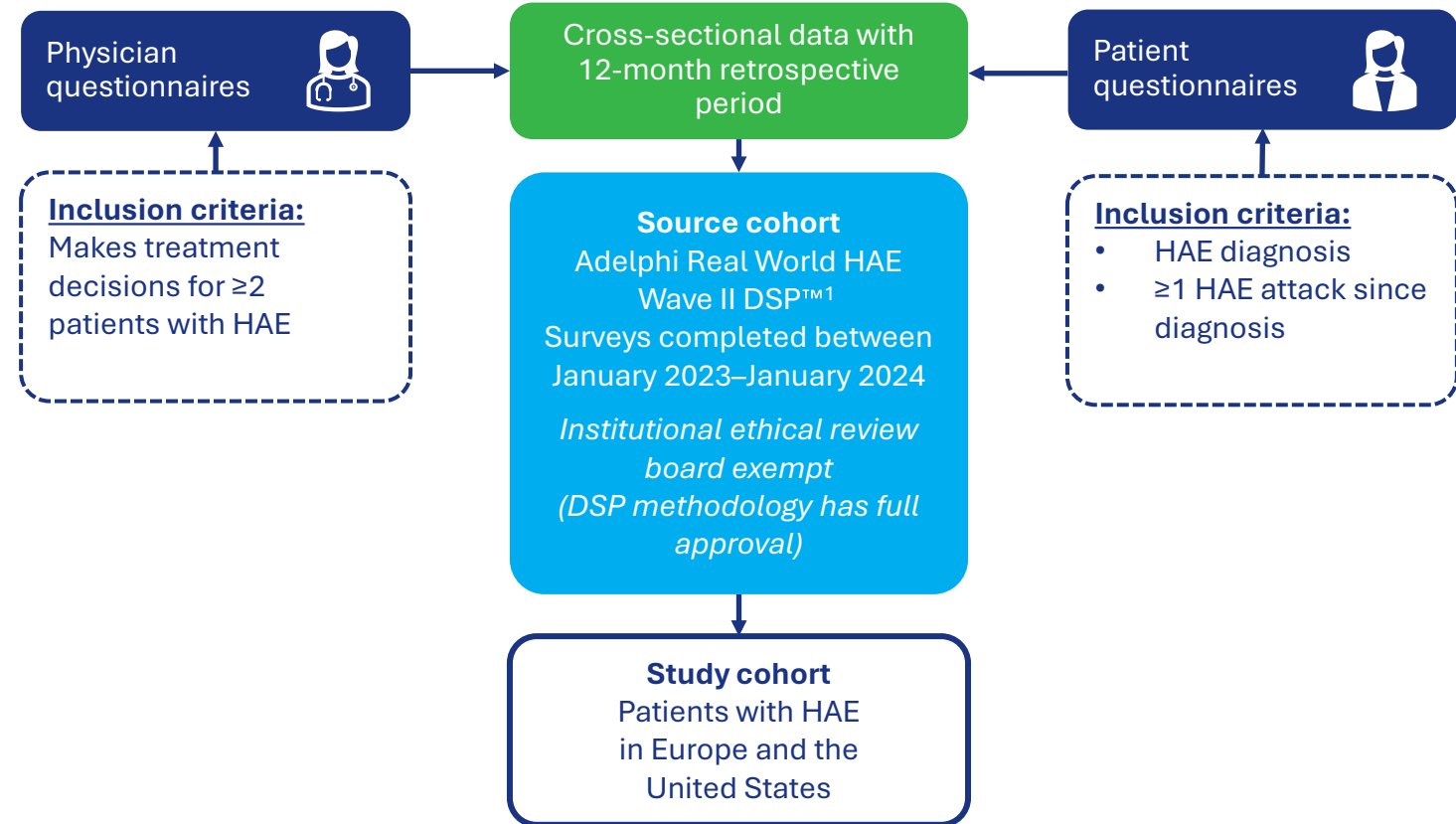
# Real-world cross-sectional survey

**Study objective:** Assess the relationship between treatment and outcomes of patients with HAE prescribed LTP alone and ODT alone in a real-world setting.

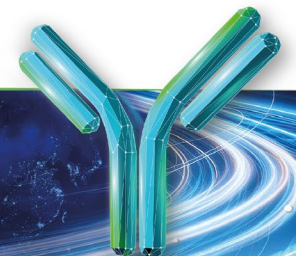
**Study cohort:** 162 physicians reported data for 601 patients with type 1/2 HAE from Europe and the United States collected via the Adelphi HAE Wave II Disease Specific Programme™ (DSP).

**Methodology:** Data were analysed by applying inverse probability weighted regression adjustment (IPWRA).

IPWRA applies inverse probability of treatment weighting (IPTW) to adjust for confounding with regression modelling.



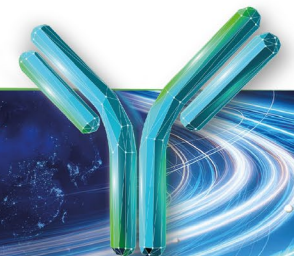
HAE, hereditary angioedema; LTP, long-term prophylaxis; ODT, on-demand treatment. 1. Anderson P, et al. *Curr Med Res Opin.* 2023;39:1707-15.



# Patient demographics and clinical characteristics

Of the 601 patients, 41% were taking LTP alone, and 59% were taking ODT alone.

	Patients prescribed LTP alone <sup>a</sup> (n=249)	Patients prescribed ODT alone <sup>b</sup> (n=352)
<b>Age</b> (years), mean ± SD [range]	35.3 ± 13.2 [9–70]	31.7 ± 15.0 [5–82]
<b>Female</b> , n (%)	140 (56)	176 (50)
<b>HAE type</b> , n (%)		
Type 1	190 (76)	275 (78)
Type 2	59 (24)	77 (22)
<b>Number of HAE attacks in 12 months prior to data collection</b> , mean ± SD [range]	1.4 ± 2.1 [0–20]	2.4 ± 2.9 [0–26]
<b>Time since diagnosis</b> (years), mean ± SD [range]	6.6 ± 7.2 [0–45] <sup>a</sup>	5.9 ± 6.5 [0–38] <sup>b</sup>
<b>Time on treatment</b> (years), mean ± SD [range]	2.6 ± 2.8 [0–26]	3.5 ± 3.6 [0–25.6]



# Geographical distribution of patients

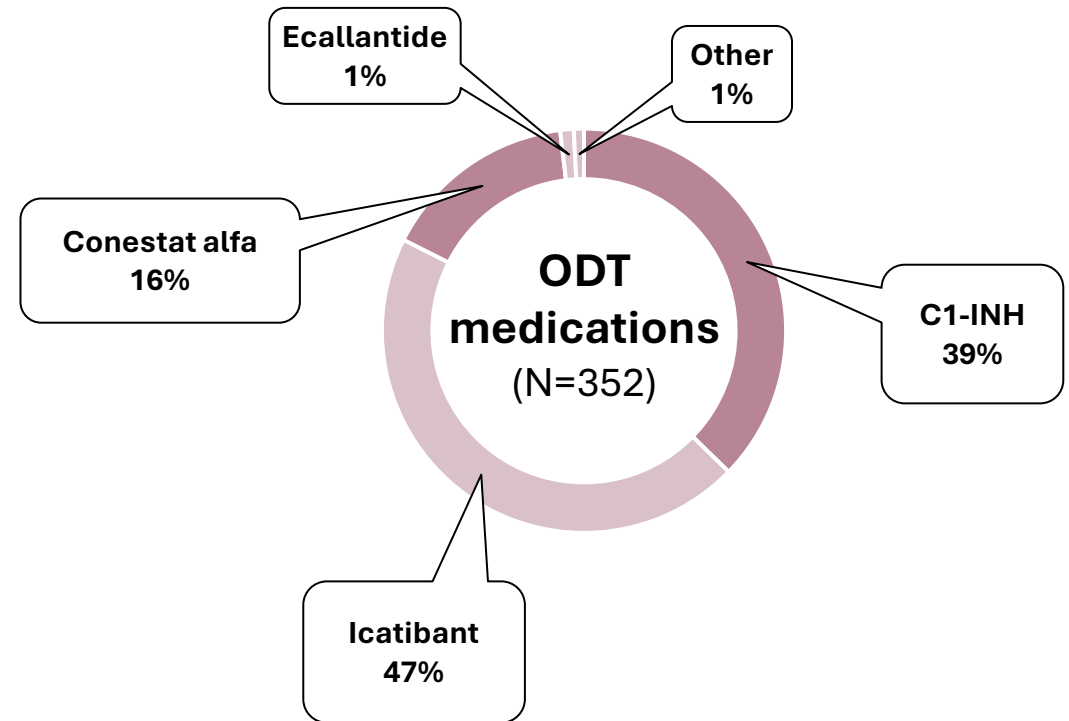
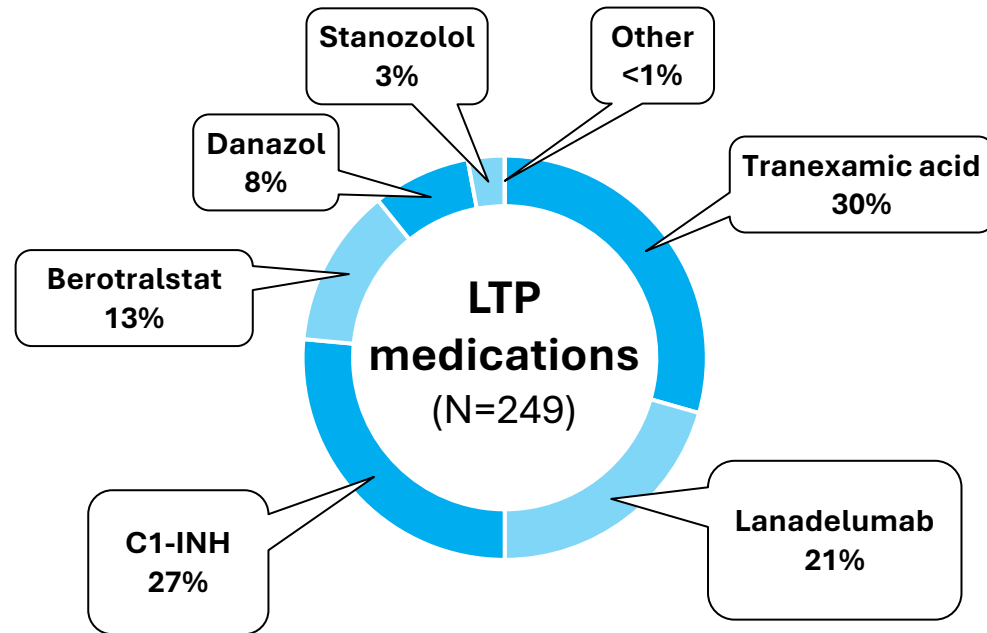
	Patients prescribed LTP alone <sup>a</sup> (n=249)	Patients prescribed ODT alone <sup>b</sup> (n=352)
<b>Country, n (%)</b>		
Europe	116 (47)	269 (76)
France	25 (10)	49 (14)
Germany	28 (11)	120 (34)
Italy	49 (20)	30 (9)
Spain	14 (6)	59 (17)
UK	0 (0)	11 (3)
US	69 (28)	73 (21)
Japan	64 (26)	10 (3)



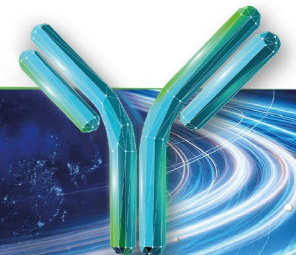
HAE, hereditary angioedema; LTP, long-term prophylaxis; ODT, on-demand treatment. <sup>a</sup>LTP alone refers to patients who were receiving a LTP without an ODT at time of survey. <sup>b</sup>ODT alone refers to patients who were receiving an ODT without LTP at time of survey.



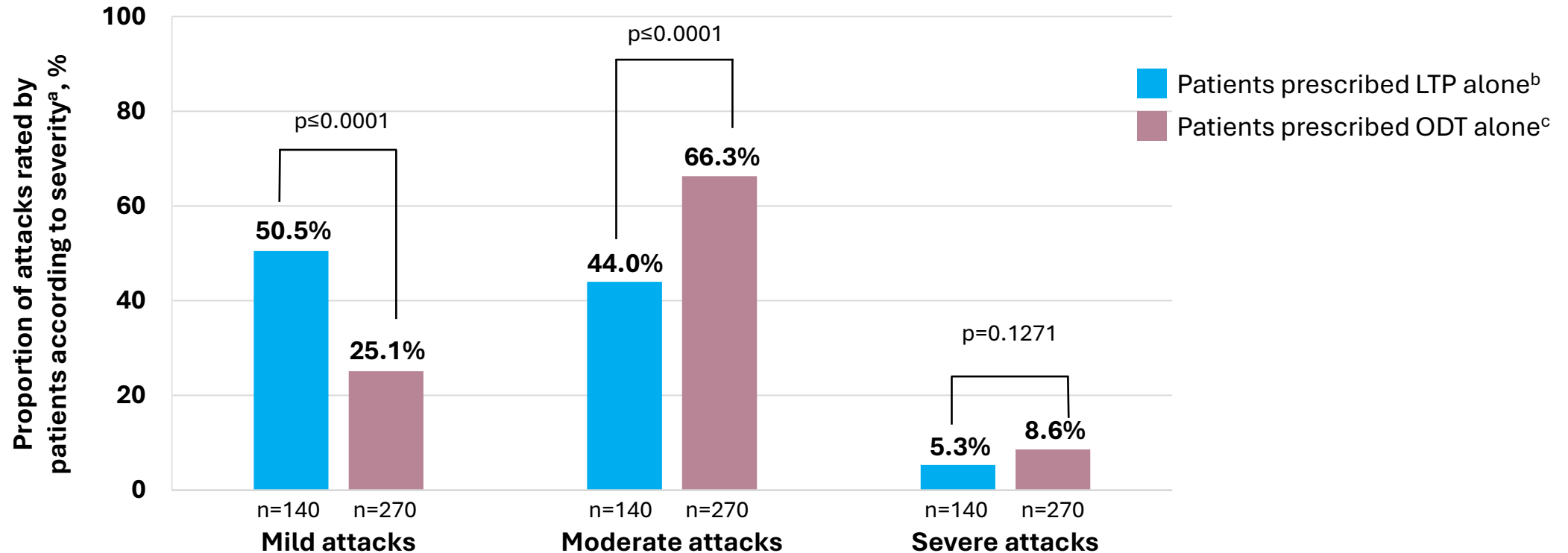
# Currently prescribed medications for LTP and ODT<sup>a</sup>



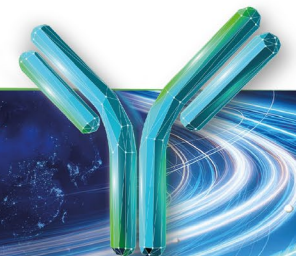
C1-INH, C1-inhibitor; LTP, long-term prophylaxis; ODT, on-demand treatment. <sup>a</sup>Some patients were prescribed more than one medication; percentages shown are out of total number of patients for LTP and ODT, respectively.



# A higher proportion of mild attacks were experienced by patients prescribed LTP than ODT in the 12 months prior to survey

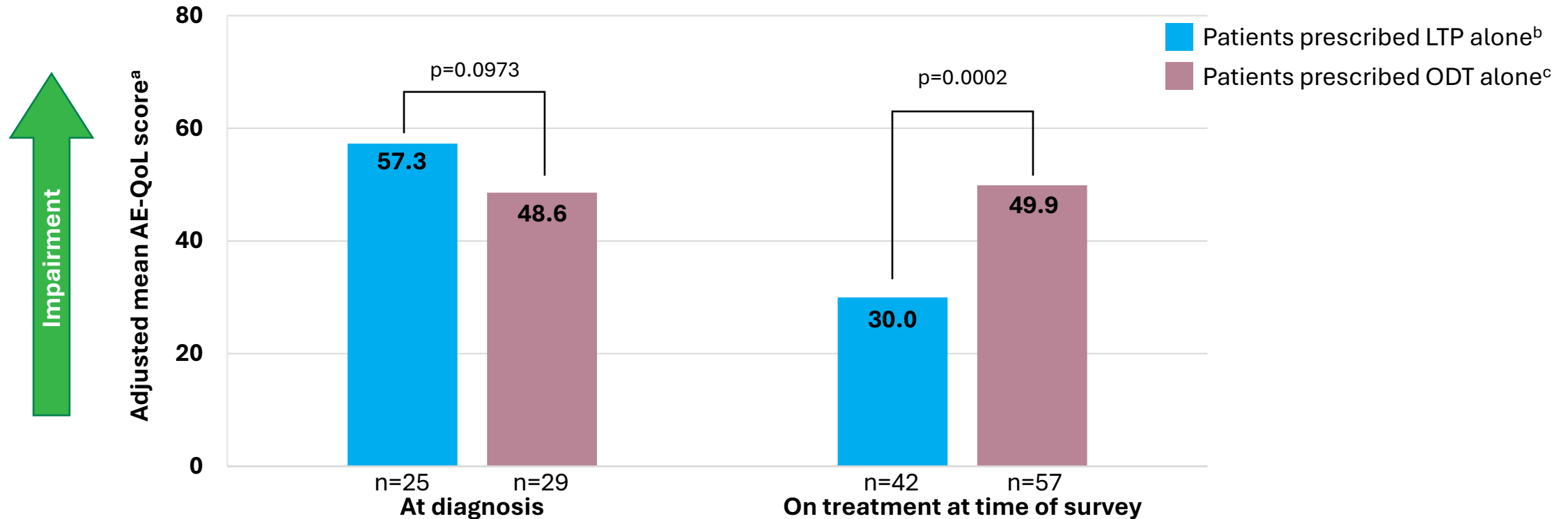


LTP, long-term prophylaxis; ODT, on-demand therapy; n, number of patients. <sup>a</sup>Attack severity data provided for patients who experienced an attack in the 12 months prior to survey. <sup>b</sup>LTP alone refers to patients who were receiving a LTP without an ODT at time of survey. <sup>c</sup>ODT alone refers to patients who were receiving an ODT without LTP at time of survey.



# Less impairment of health-related quality of life (HRQoL) reported by patients prescribed LTP alone than ODT alone

Angioedema Quality of Life Questionnaire (AE-QoL) was used to evaluate HRQoL.



HAE, hereditary angioedema; HRQoL, health-related quality of life; IPWRA, inverse probability weighted regression adjustment; LTP, long-term prophylaxis; n, number of patients; ODT, on-demand treatment. <sup>a</sup>Adjusted mean is the model predicted average outcome for each treatment group (LTP vs ODT), estimated using IPWRA. This method combines inverse probability weights with outcome regression model to adjust for covariates (age, sex, location of most recent HAE attack and days since most recent HAE attack). The reported means reflect the expected score for each treatment group after adjusting for difference in baseline characteristics. <sup>b</sup>LTP alone refers to patients who were receiving a LTP without an ODT at time of survey. <sup>c</sup>ODT alone refers to patients who were receiving an ODT without LTP at time of survey.



# Conclusion

In this study, patients with HAE **prescribed LTP alone**<sup>a</sup> in the last 12 months

- experienced more mild attacks than moderate or severe attacks
- had significantly better HRQoL at the time of the survey

compared with those **prescribed ODT alone**<sup>b</sup>.



This real-world, cross-sectional survey analysis suggests that both LTP and ODT play important roles in HAE management, and corroborates international guidelines that recommend patients with HAE on LTP must always have ODT available at all times.<sup>1</sup>

Limitations of analysis: All LTP or ODT were combined which does not allow differences between therapies to be investigated.



HAE, hereditary angioedema; HRQoL, health-related quality of life; LTP, long-term prophylaxis; ODT, on-demand treatment. 1. Maurer M, et al. *Allergy*. 2022;77:1961-90. <sup>a</sup>LTP alone refers to patients who were receiving a LTP without an ODT at time of survey. <sup>b</sup>ODT alone refers to patients who were receiving an ODT without LTP at time of survey.

