

Abstract from HAEi Global Leadership Workshop, Frankfurt 6–9 Oct 2022

The Global and Regional Impact of Hereditary Angioedema (HAE) Attacks on Mental Health, Activities of Daily Living and Quality of Life

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Rationale: HAE is characterized by unpredictable, recurrent episodes of angioedema affecting various parts of the body. This study describes patient-reported impact of HAE attacks on the mental health, quality of life and activities of daily living.

Methods: The US HAE Association (HAEA) and HAE International (HAEi) invited HAE patients to participate in a 2-hour focus group between November 2021 and March 2022. Participants provided informed consent and completed pre- and post- focus group surveys.

Results: Respondents included 32 patients; 23 (72%) from the United States (US) and 9 (28%) International. The mean age overall was 33yrs (range 15-72). Participants were categorized into 'adolescent, 15-18yrs' or 'adult, 19+yrs' and had a mean of 33 attacks (median 18, range 0-170) annually. Treatment was on-demand therapy only (65% [59% US/78% International]) or prophylactic with on-demand 35% (41% US/22% International). Overall, 67% (62% US/79% International; 68% adolescent/67% adult) reported that if an attack was not treated, daily plans needed to be changed, and 58% (45% US/89% International; 67% adolescent/56% adult) stated they could not participate in important events or activities. Overall, 39% noted that the unpredictability of attacks cause anxiety and negatively impact their mental health (41% US/33% International; 17% adolescent/44% adult); 19% described managing HAE as time-consuming (23% US/11% International; 0% adolescent/24% adult). Nearly half (49% US/47% International; 28% adolescent/54% adult) reported feeling 'less than 100% themselves' because of their HAE.

Conclusion: These results highlight the important disease burden of HAE attacks on mental health, daily activities and overall quality of life. Although recent advances in treatment options have been significant, the need for further improvement has been identified by the global HAE community.