Impact of Hereditary Angioedema (HAE) Attacks on Quality of Life and Activities of Daily Living

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Background

- HAE is characterized by recurrent and unpredictable episodes of subcutaneous or submucosal swelling affecting the abdomen, extremities, genitalia, face, and larynx.
- HAE attack frequency is highly variable among individuals and over time.
- Average for untreated patients, every 2 weeks.
- Symptoms of an HAE attack may be painful and debilitating, potentially interfering with the ability to conduct daily activities (work, school, social activities).
- Although self-administration of on-demand parental treatments has enhanced overall HAE attack management, HAE disease burden may remain.

Objectives

- To listen to HAE patients’ experiences and recommendations.
- Learn about how patients recognize the initial signs and symptoms related to HAE attacks.
- Identify factors that influence patient’s decision making process for initiating, delaying, or forgoing on-demand treatment for HAE attacks.
- Identify the impact that delaying or forgoing on-demand treatment has on daily activities.
- This report describes the impact of HAE attacks on quality of life and activities of daily living for people with HAE.

Methods

- People living with HAE were invited to participate in a focus group discussion in collaboration with US HAE Association (HAEA) and HAE International (HAI).
- In total, 32 individuals with HAE participated in one of four 2-hour focus groups, held between November 2021 and March 2022.
- Focus group attendees were invited to complete a pre-focus group survey, n=1 respondent only did the pre-focus survey, n=29 completed both.
- Inclusion criteria enriched for patients treating attacks with on-demand only therapy. Additional information regarding the HAE attack history in secondary and tertiary care was obtained in some cases.
- This report describes the impact of HAE attacks on quality of life and activities of daily living for people with HAE.

Baseline demographics

| Location | United States | International
| Current Age, yr (Mean [Range]) | 33 (15 - 71) | 36 (14 - 58)
| Age of Diagnosis, yr (Mean [Range]) | 16 (0 - 40) | 17 (0 - 40)
| Type of Therapy | On-demand only | 68% | 72% |
| Prophylaxis with on-demand for breakthrough attacks | 32% | 28% |
| Attacks Per Year, Median (Range) | 3 (0 - 170) | 3 (0 - 170) |

How often (percent of time) do you feel less than your 100% self because of HAE?

| When you do not treat an attack, how often do you plan for the day change?
| Total (n=32)* | Adolescent (15-18yr) (n=17)* | Adult (19+yr) (n=15)* |
| Mean, (Range) | 0% - 100% | 0% - 100% | 0% - 100% |

Results

What is the most significant impact of HAE on your life?

| Total (n=32)* | Adolescent (15-18yr) (n=17)* | Adult (19+yr) (n=15)* |
| Prophylaxis with on-demand for breakthrough attacks (n=10)* |
| I cannot count on participating in important events and activities in my life | 58% | 67% | 56% |
| Unpredictability of attacks causes anxiety and negatively impacts my mental health | 39% | 17% | 44% |
| It is time-consuming to manage HAE (e.g., managing prescriptions, insurance, attacks) | 19% | 8% | 24% |
| I have become resilient and determined to advocate for myself and others | 16% | 33% | 12% |
| I feel judged by poorly informed healthcare providers and by society in general | 13% | 17% | 12% |
| I question having children that might inherit HAE | 10% | 0% | 12% |
| Nothing | 6% | 17% | 4% |

Conclusions

- HAE attacks produce a significant disease burden on mental health, daily activities, and overall quality of life.
- An untreated attack resulted in a change of daily plans for two thirds of respondents.
- Nearly half felt ‘less than 100% themselves’ due to HAE.
- Although there have been clear advancements in treatment options, there remains a significant opportunity to improve the lives of people with HAE.

References


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