

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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Disclosures

In relation to this presentation, the authors declare the following, real or perceived conflicts of interest:

Paula J. Busse – Advisory Board/Consultant and/or Grant/Research Support: CSL Behring, KalVista Pharmaceuticals, BioCryst Pharmaceuticals, Takeda, Regeneron, Novartis

Teresa Caballero – Advisory Board/Consultant and/or Grant/Research Support: BioCryst Pharmaceuticals, CSL Behring, KalVista Pharmaceuticals, Merck & Co, Novartis, Octapharma, Pharming, and Shire/Takeda.

Sally van Kooten – is an employee of KalVista Pharmaceuticals, Inc.

Sherry Danese – has received consultant fees from KalVista Pharmaceuticals, Inc.

Ledia Goga – is an employee of KalVista Pharmaceuticals, Inc.

This study was supported by KalVista Pharmaceuticals, Inc.

Introduction

HAE is characterized by recurrent and unpredictable episodes of subcutaneous or submucosal swelling affecting the abdomen, extremities, genitals, face, and larynx

- Symptoms of an HAE attack may be painful and debilitating, potentially interfering with the ability to conduct daily activities (work, school, leisure activities)¹

HAE attack frequency is highly variable among individuals and over time²

- Average for untreated patients, every 2 weeks (range from 'very rarely' to 'every 3 days')

Due to concerns about the unpredictability of attacks, serious outcomes (asphyxiation) and genetic inheritance, those with HAE tend to have higher levels of depression and anxiety³

HAE patients may experience significant impacts on their daily lives and these experiences may differ based on the region in which they live.

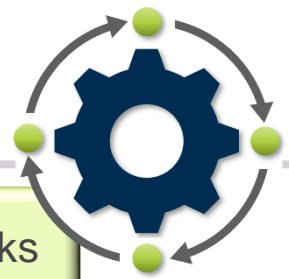
Although self-administration of on-demand treatments has enhanced overall HAE attack management, HAE disease burden may remain.

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Objective & Methods

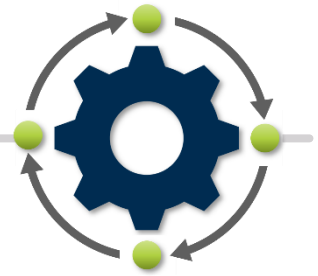


The objective of this study was to characterize the impact of HAE attacks on the quality of life and activities of daily living for people with HAE

Methods

- Thirty-two individuals with HAE participated in one of four 2-hour focus groups, held between November 2021 and March 2022
- Informed consent was obtained
- Participants completed a pre- and post-focus group online survey
- Inclusion criteria were enriched for patients utilizing on-demand treatment only, versus those experiencing breakthrough attacks while on prophylactic treatment

Methods



- Survey included multiple-choice, rank-scale, rank-order or open-ended questions.
 - 5-10 minutes to complete
- Patient privacy was protected by use of pseudonyms; patient health records were not accessed
- Analysis was performed using descriptive statistics
 - Continuous variables summarized as means, medians, and ranges
 - Categorical variables summarized as counts and percentages

Respondent Location



Adult and adolescent participants recruited in collaboration with US HAE Association (HAEA) and HAE International (HAEi) patient advocacy organizations

Respondent Demographics

A total of 32 respondents completed either the pre- or post-survey*

Baseline demographics	Total (n=32)*	US (n=23)	International** (n=9)
<u>Region</u>			
US	72%	100%	–
International	28%	–	100%
Current Age (Mean, Range)	33 (15 - 72)	33 (15 - 72)	31 (22 - 43)
Gender, Female (n, %)	20 (63%)	16 (70%)	4 (44%)

*A total of n=32 respondents completed either the pre- or post-survey. n=2 respondents only did the pre-survey, n=1 respondent only did the post-survey, n=29 completed both.

** Australia (n=1), UAE (n=1), Germany (n=2), Nordics (n=1), Poland (n=2), Saudi Arabia (n=1), UK (n=1)

Respondent Characteristics

Characteristic	Total (n=32)*	US (n=23)	International** (n=9)
Age of Diagnosis (Mean, Range)	16 (0 - 40)	17 (3 - 40)	12 (0 - 33)
<u>Type of Therapy</u>			
On-demand only	68%	64%	78%
Prophylaxis with on-demand for breakthrough attacks	32%	36%	22%
Attacks Per Year (Mean, Median, Range)	33, 17.5 (0 - 170)	24, 16.25 (0 - 100)	56, 40 (1 - 170)

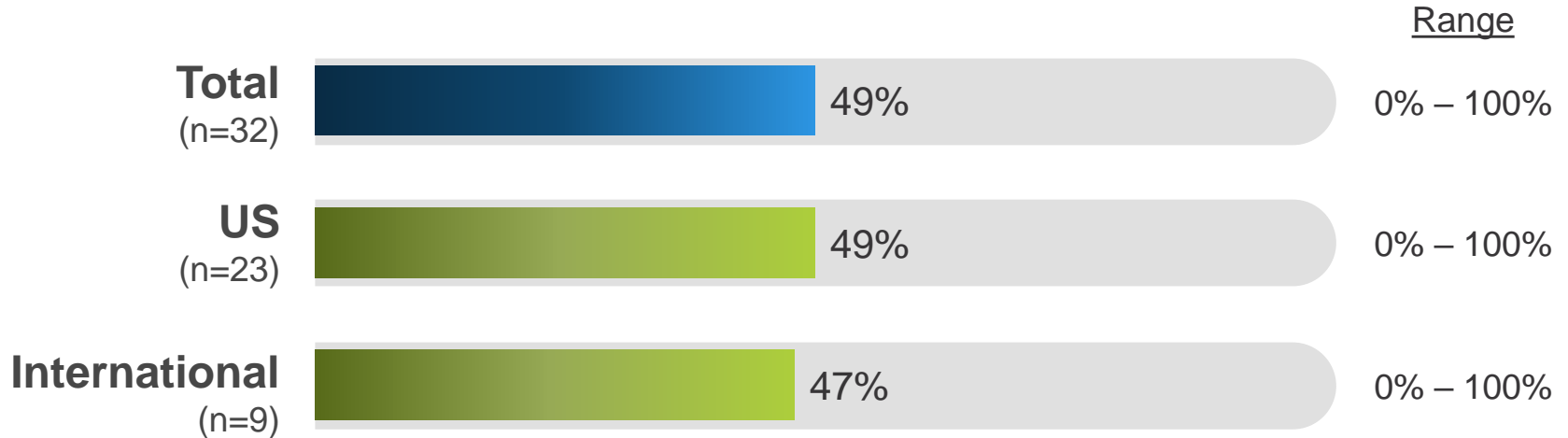
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Patients feel like 'less than their 100% self' because of HAE nearly half the time



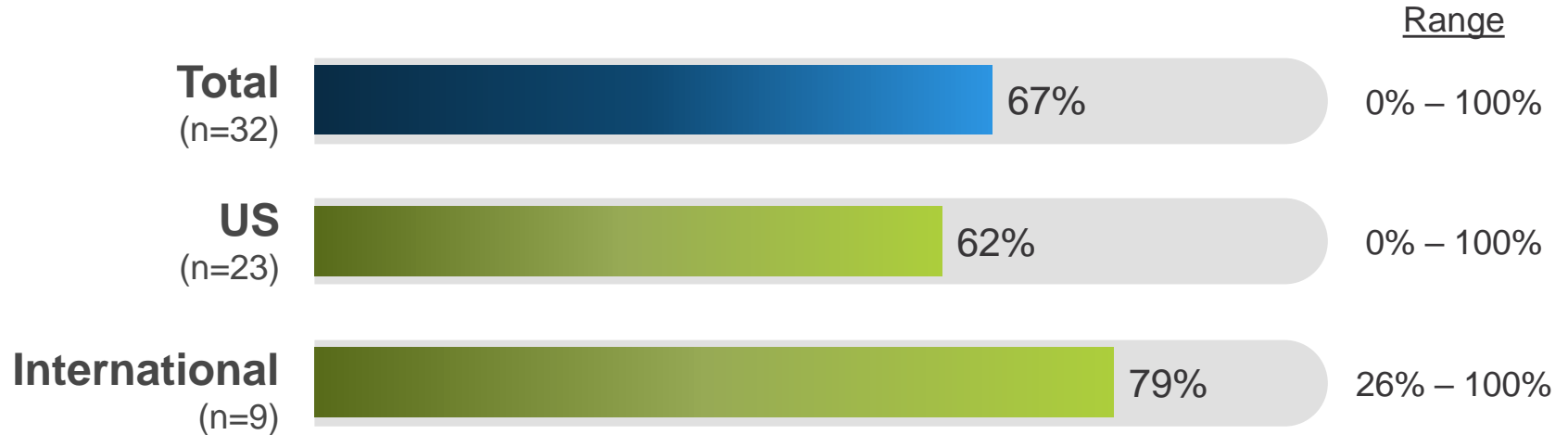
How often (percent of time) do you feel less than your 100% self because of HAE?



When patients do not treat an attack, their plans for the day change two-thirds of the time



When you do not treat an attack, what percentage of the time do your plans for the day change?



Unpredictable attacks and time spent managing treatment of HAE causes substantial anxiety and lowers quality of life



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

---- Percent of respondents that mention ----



I cannot count on participating in important events and activities in my life

Total (n=32)*	US (n=23)	International** (n=9)
58%	45%	89%
39%	41%	33%
19%	23%	11%
16%	14%	22%
13%	14%	11%
10%	14%	0%
10%	5%	22%



Unpredictability of attacks causes anxiety and negatively impacts my mental health

It is time-consuming to manage HAE (e.g., managing prescriptions / insurance, managing attacks)

I have become resilient and determined to advocate for myself and others

I have to endure painful and sometimes disfiguring attacks

I feel judged by poorly informed healthcare providers and society in general

I question having children that might inherit HAE

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Conclusions



Results highlight the significant impact that HAE attacks have on people's ability to participate in daily activities and how the unpredictability of attacks negatively impacts their lives



Almost half the time, patients feel, 'less than their 100% self' because of their HAE



Majority ranked missing out on important events in their lives and anxiety associated with unpredictability of HAE attacks as the most impactful factors

Thank you to all survey participants, and those who assisted in the development of the survey, and participant recruitment

