

In Their Own Words - Patient Descriptions of the Earliest Recognition of Hereditary Angioedema (HAE) Attack Onset

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Background

- Hereditary angioedema (HAE) is a genetic disease resulting in deficiency (type I) or dysfunction (type II) in the complement-1 esterase inhibitor (C1-INH) protein and subsequent uncontrolled activation of the kallikrein-kinin system (KKS).
- People living with HAE experience painful and debilitating attacks of tissue swelling in various locations of the body that can be life-threatening depending on the location affected.
- Symptoms of an HAE attack can potentially interfere with the ability to conduct daily activities (work, school, social activities)¹
- Initial HAE attack onset can be highly individualized, underscoring the complex nature of how these attacks manifest.

Objective

- The objective of this survey was to characterize the way people living with HAE recognize and describe the onset of an attack

Methods

- People living with HAE were recruited by the US Hereditary Angioedema Association (HAEA) to complete an online survey
- The survey was self-reported, and took respondents approximately 20 minutes to complete
- The survey was completed by 107 individuals between September 6 and October 19, 2022; response rate 69% (107/155)
- Respondents provided consent for their data to be used anonymously or in aggregate
- Analysis was performed using descriptive statistics

References

- Bygum A. Hereditary angioedema—consequences of a new treatment paradigm in Denmark. Acta Derm Venereol. 2014;94(4):436–41.

Disclosures

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Results

Table 1. Respondent Characteristics

Characteristic	Total (n=107)
Age, mean	41yrs (Range 16-83 yrs)
Age category, n (%)	
24yrs and younger	14 (13.1%)
25yrs to 44yrs	51 (47.7%)
45yrs and older	42 (39.3%)
Gender, n (%)	
Female	86 (80.4%)
Male	21 (19.6%)
Type of therapy, n (%)	
On-demand only	53 (49.5%)
Prophylaxis with on-demand	54 (50.5%)
Level of anxiety when anticipating on-demand treatment*	
High anxiety (8-10 on scale of 1 to 10)	26 (24.3%)
Moderate anxiety (4-7 on scale of 1 to 10)	34 (31.8%)
Low anxiety (2-3 on scale of 1 to 10)	28 (26.2%)
No anxiety (1 on scale of 1 to 10)	19 (17.8%)
Time to HAE attack treatment	
Immediately treat all attacks	15 (14.0%)
Do not immediately treat all attacks	92 (86.0%)

*Anxiety scale 1 "not anxious" to 10 "extremely anxious"

Figure 1. On-demand Treatments Used

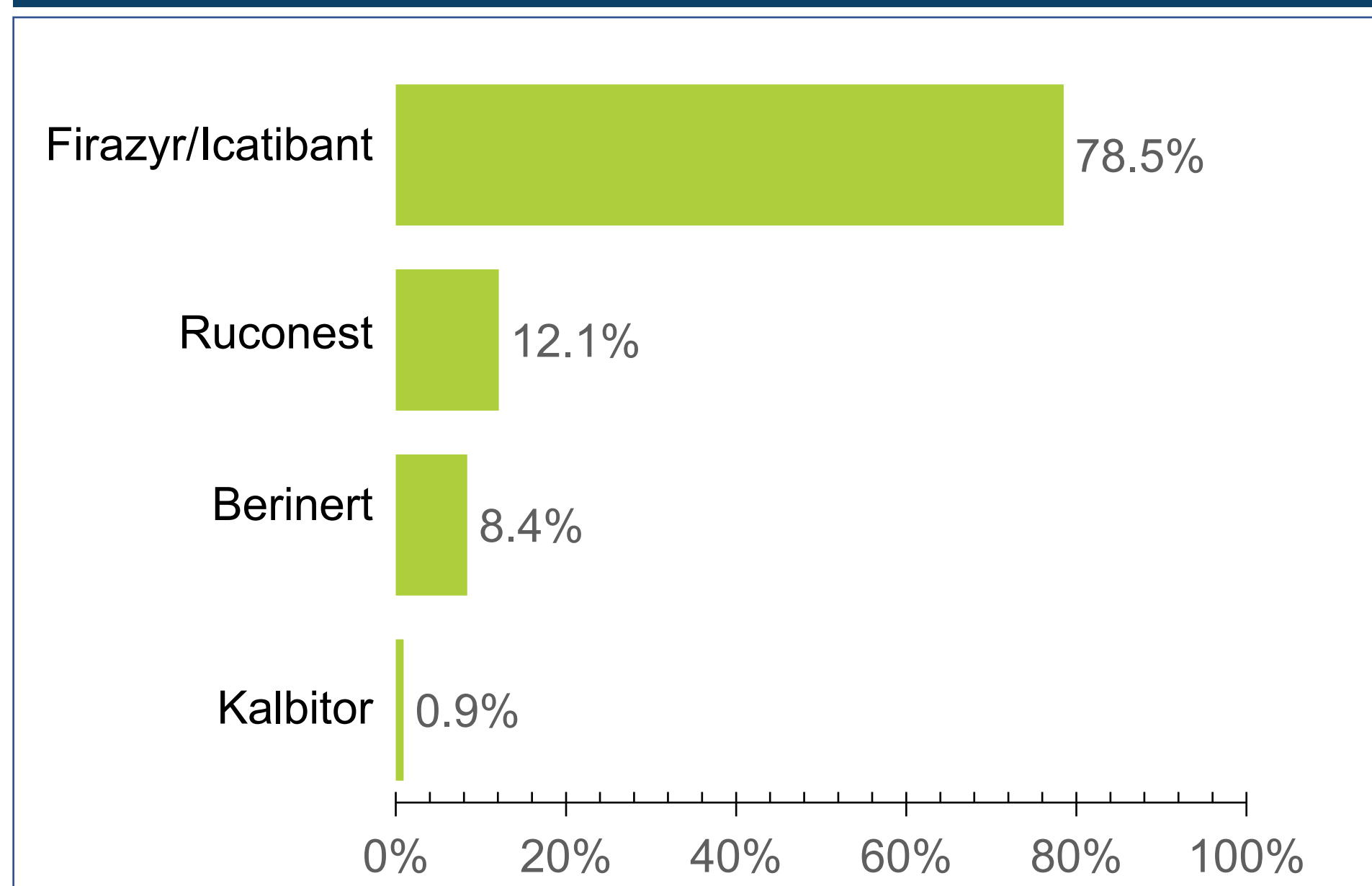


Figure 2. Words Used by Respondents to Describe When an HAE Attack has Started

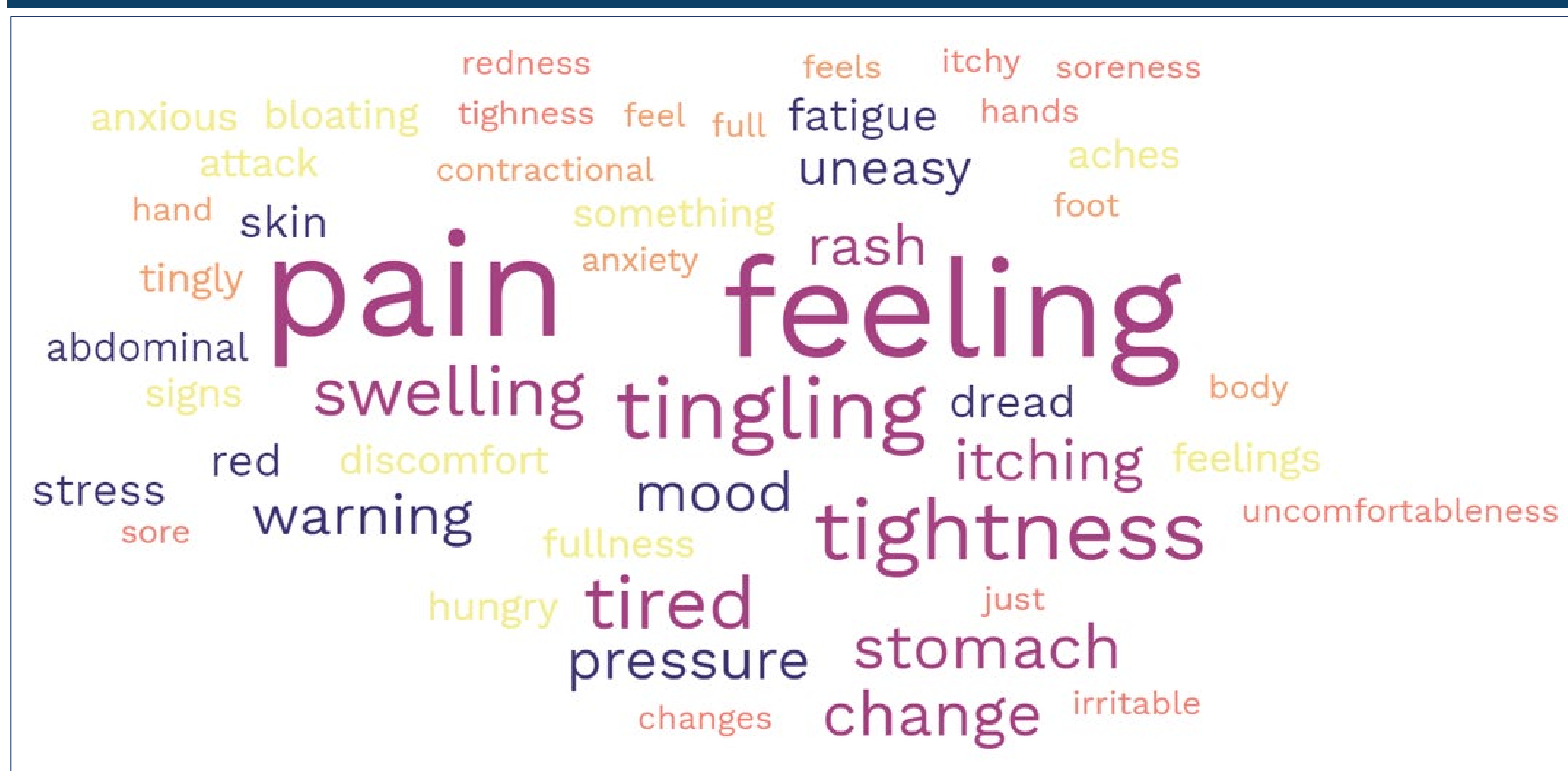


Figure 3. Common Themes of Words Used to Describe HAE Attack Onset



Table 2. Statements Used by Respondents to Describe the Onset of an HAE Attack

"I feel uncomfortable - I feel 'off.'"
"I feel a tightness in my hands or feet."
"I get an uneasy sensation."
"I get sharp stomach pain. My throat begins to itch and scratch."
"I get really sleepy."
"I feel uneasy."
"My mood changes for no reason."
"I feel bloated. It is a sense of fullness."
"I feel cramping and tingling."
"I get red spots around my hands and a 'hard' feeling on my skin surface."
"I feel pain in my joints and tender areas. I get hives."
"I get severe acid reflux and a 'full' feeling."
"Something just doesn't feel right."

Conclusions

- Survey results highlighted that the descriptions used by people living with HAE to describe attack onset are variable and highly individualized
- People living with HAE are able to consistently recognize and describe the initial onset of an HAE attack
- Additional studies are needed to explore if these findings align with patient behaviors when treating HAE attacks
- These findings may help to inform future treatment discussions and may enhance aspects of the physician/patient dialogue

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Please scan this QR code to view the poster after the congress.

