Poster 215

The Patient Experience Of Hereditary Angioedema: Findings From A Racially Diverse Sample Of Adult Patients

Aaron Yarlas[1], Jordan Valentine[1], Laura Bordone[1], April Foster[2], Laura Tesler Waldman[2], Lynne Broderick[2]
[1]Ionis, Carlsbad, CA, USA • www.ionis.com; [2]QualityMetric, an IQVIA Business, Johnston, RI, USA

BACKGROUND

- Hereditary angioedema (HAE)-related symptoms and impacts on health-related quality of life (HRQoL) have been well-documented in the literature[1-9] and include impacts on:
  - Physical functioning
  - Emotional functioning
  - Social functioning
  - Work productivity
- However, these findings are based on samples of primarily White patients, limiting their generalizability to adults of other races with HAE[1,2,4,6-13]

OBJECTIVE

- The objective of this qualitative study was to explore the patient experience of HAE among a racially diverse sample of adults

METHODS

Study Design

- This was a cross-sectional, non-interventional, qualitative study consisting of 60-minute, one-on-one, concept elicitation interviews designed to capture the disease-related experiences of a diverse sample of adults with HAE, including their symptom experience, attack triggers, impacts on HRQoL related to HAE attacks, and treatment experiences

Eligibility Criteria and Recruitment

- A purposive sampling strategy was used to recruit 16 adults with HAE, with a target of at least 8 participants who were non-White
- Participants were recruited through a partnership with a United States (US)-based, HAE-specific, patient advocacy group
- Individuals were eligible to participate in the study if they: were age 18 or older, had been told by a clinician that they have type I or type II HAE, had at least 1 HAE attack in the last 6 months, lived in the US, spoke and read English, and were able to provide confirmation of an HAE diagnosis
  - Individuals were excluded if they had HAE with normal C1-inhibitor

Data Collection

- Eligible participants took part in a single audio-recorded interview conducted by trained interviewers who followed an institutional review board (IRB)-approved, semi-structured interview guide

Data Coding and Analysis

- Transcripts were coded in NVivo qualitative software (v.14; Lumivero, 2023) using inductive thematic analysis methods to identify patterns in participant responses concerning the relevant and important elements of their HAE experiences
- Assessment of saturation showed that 88% and 93% of concepts emerged by the 8th and 12th interviews, respectively

RESULTS

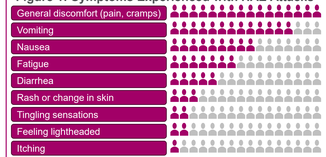
Sample

- Sixteen adults with HAE took part in this study; 12 (75%) participants self-identified as non-White
- All participants (n=16; 100%) had been prescribed an acute treatment at the time of their interview
- Most (n=13; 81%) were on a prophylactic regimen at the time of their interview

Symptoms

- In addition to the swelling that accompanies every HAE attack, participants also experienced:

Figure 1: Symptoms Experienced with HAE Attacks



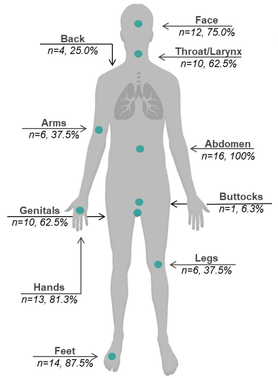
- Most participants (n=13; 81%) reported experiencing prodromal symptoms (including fatigue and tingling a few days to a few hours before an attack)

Table 1: Participant Characteristics (N=16)

Age, years	
Mean (SD)	43.6 (13.0)
Median	47.0
Range	19.0-63.0
Q1-Q3	36.5-53.0
Sex	
Male	6 (37.5)
Female	10 (62.5)
Race/Ethnicity	
Black	6 (37.5)
Caucasian or White	4 (25.0)
Hispanic or Latino	3 (18.8)
American Indian or Alaska Native	1 (6.3)
Other: Mixed (Black and Caucasian/White)	1 (6.3)
Other: Albanian	1 (6.3)
Current Treatment (At Time of the Interview)	
Long-term prophylactic treatment	13 (81.3)
Acute treatment[a]	16 (100)
# Attacks in Past 6 Months[b]	
Mean (SD)	7.1 (7.4)
Median	3.0
Range	1-30
Q1-Q3	2.9-10.0

[a]Three participants indicated having 2 treatments on-hand (e.g., in case one did not work) and 1 self-reported acute use of a prophylactic treatment.
[b]Individual responses that indicated a range in the number of attacks experienced over the past 6 months (e.g., 1-2) were averaged.
Abbreviations: Q, quartile; SD, standard deviation

Figure 2: Bodily Locations of HAE Attacks



- In addition to the bodily locations shown in the figure, 1 participant (6%) each reported attacks in the breasts, hips, ureter, chest, and brain

Figure 3: Participant Quotes Describing HAE Attacks

> I swelled up a few times with my face, my throat never swelled up. So, it was just an exterior thing, but I look like—like a monster [laughs] almost. I call my spirit animal the puffer fish—because everything swells. The eyes, the nose, the lips, everything. (female, age 37)

> If you swell in the limbs that do things, it-it limits your mobility and what you can get done…[if] your entire leg is swollen, you can't walk, or if your entire arm is swollen, you can't drive…the arm and the hand swellings and leg—like, all that stuff's very inconvenient and, of course, also uncomfortable. (male, age 21)

> I'd rather have 20 babies at one time [than have an abdominal attack]…it's an unbearable pain, the discomfort, the throwing up, the diarrhea…the which way should I lay down? You can't sleep because if you sleep, your stomach is, is contracting. It's just contracting…It's just ongoing trigger, one after—a pain after the other. (female, age 54)

Frequency of Attacks

- Participants self-reported experiencing a range of 1 to 30 attacks during the previous 6 months
- All participants taking a prophylactic treatment (n=13 out of 13; 100%) described a noticeable decrease in the frequency and severity of their attacks since starting treatment

Severity of Attacks

- Laryngeal, abdominal, and facial attacks were generally considered more severe than attacks elsewhere in the body
- Perception of severity of attacks in other areas of the body varied based on the level of functional impairment

Attack Triggers

- Stress was a known trigger for many participants
- Food-related triggers were specific to certain foods (e.g., pork, mayonnaise, garlic) for some participants, while for others certain types of food or beverages (e.g., spicy food, gluten, alcohol) were triggers

Figure 4: Attack Triggers

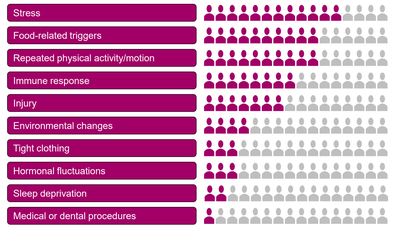


Figure 5: Participant-reported Impacts on HRQoL

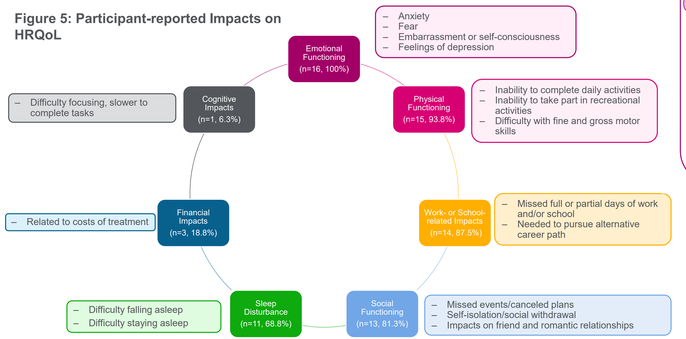


Figure 6: Participant Quotes Describing Impacts on HRQoL

> …it affects me emotionally because I—I want to be able to do the, quote unquote, "normal things" that's required of me for the day…it doesn't make me feel confident when I have the swelling…and so it does start to take a toll on me, and I see a therapist for it. (female, age 39)

> …I can't go to work when it's, like, a severe foot swell, or hand swell, or intestinal swell…right now I work in a library, so when my hand is severely swollen, I can't grip books, like, I'm not able to close my hand at all. (female, age 35)

Treatment Experiences

- Overall, participants reported satisfaction with their current prophylactic and acute treatments

Figure 7: Most Liked Aspects of Prophylactic Treatment

Figure 8: Least Liked Aspects of Prophylactic Treatment

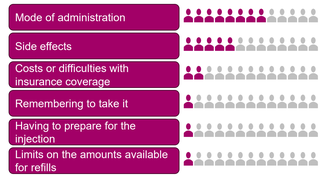


Figure 9: Most Liked Aspects of Acute Treatment

Figure 10: Least Liked Aspects of Acute Treatment

> It's a godsend, it's made me—my swells [are] way less frequent. And it's convenient, like, just taking a pill instead of having to give myself a shot or infusion. It's the best medicine I've found, yeah. (female, age 35)

> The only time I [use] my acute medication was when—when I was having abdominal attacks—or attacks to do with my throat because those are life threatening, you know? …I never used them for my hands or my feet because those—I knew those would go away soon…and they're not painful to me, you know?...When I wake up to that pain [in the stomach], uh, there's no waiting [laughs]…Just immediately, just take it now. (male, age 53)

CONCLUSIONS

- The HAE attacks described by participants, including symptoms, bodily locations of attacks, triggers, frequency, and severity, were similar to those of primarily White adults described in the literature[1,7,10-12]
- Participants experienced impacts across multiple domains of HRQoL including emotional, physical, and social functioning, and work-related impacts, all of which have been previously documented in samples of primarily White adults with HAE[1,2,4,6-8,13]
- Findings from this qualitative study demonstrate that the HAE patient experience in a racially diverse sample of adults is similar to that of the non-diverse samples reported in earlier studies

REFERENCES AND DISCLOSURES

This research was funded by Ionis. Please visit the QR code at the top of this poster to view additional disclosure and reference information.