Poster #R110

A qualitative study and conceptual model of patient experiences during and between hereditary angioedema attacks.

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BACKGROUND

- Hereditary angioedema (HAE) is a rare, genetic disorder characterized by recurrent swelling attacks affecting extremities, the gastrointestinal tract, face, genitals, and upper airways.[1]
- Few studies have comprehensively explored patient experiences across different attack phases: Prodromal (early warning signs), Acute, Recovery, and attack-free periods. Attack-free periods are often clinically regarded as symptom-free, despite growing patient reports of persistent burdens.[1-3]
- This study aimed to develop a conceptual model reflecting the lived experience of HAE across all disease phases, including symptoms, functional limitations, and psychosocial impacts during and in-between attacks.

STUDY DESIGN

- **Study Design:** Cross-sectional qualitative study with semi-structured interviews.
- **Participants:** 25 adults with HAE Type I/II recruited via US Hereditary Angioedema Association. Required ≥5 lifetime attacks, including one within 90 days, and ≥1 severe attack or attack affecting throat/face/abdomen/hands/feet in lifetime.
- **Data Collection:** Background questionnaire plus 60-minute interviews exploring in-between attack periods and detailed attack accounts using visual aids for attack phases.
- **Analysis:** Thematic analysis with MAXQDA software. Conceptual model developed based on findings.

RESULTS

Sample Demographics

- The study included 25 participants with a mean age of 44 years (SD 9.7); 76% were female and 80% were White/Caucasian. The mean time since diagnosis was 25 years (SD=19). Participants reported a mean of 27 attacks in the past year (median 18; range 3–100). Most had type I HAE (80%). The majority (84%) had been prescribed long-term prophylaxis (LTP).

Conceptual model (Figure 1):

- **Illustrates the complex nature of living with HAE. The model depicts both day-to-day disease management and attack experiences across all phases, with moderating factors that influence the overall disease experience.**
- The yellow boxes show the experience between attacks.
- The red boxes show attack symptoms and impacts across phases, which vary depending on attack location and severity.

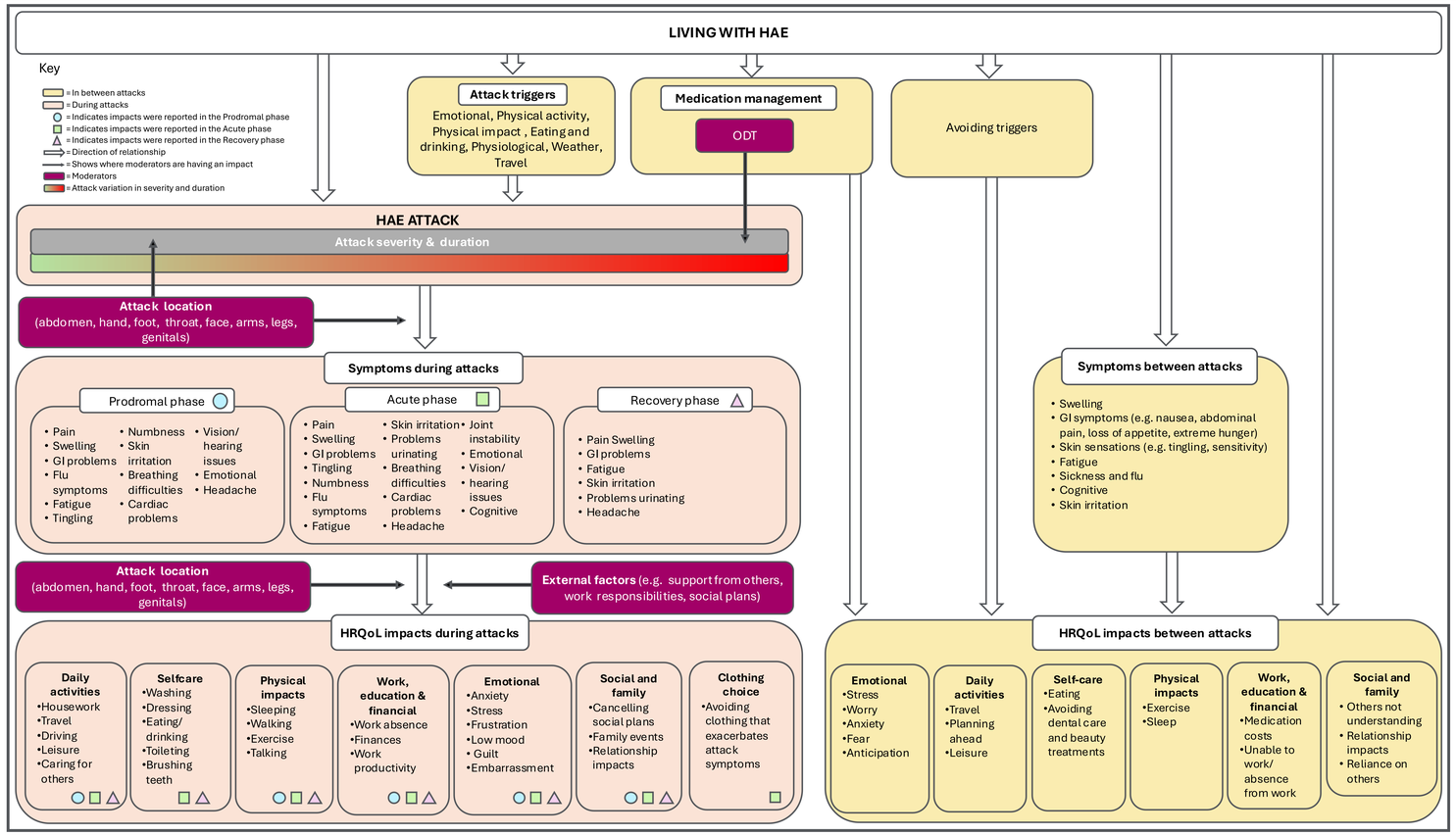

FIGURE 1: Conceptual model showing interrelationships of symptoms, impacts, and moderators across HAE phases

CONCLUSIONS

- Individuals with HAE experience substantial symptoms and impacts in-between attacks, and during three phases of attack (prodromal, acute and recovery).
- Future research should build on this work by assessing health-related quality of life (HRQoL) impacts frequently, both in observational studies and in clinical practice in order to fully capture the impact of HAE in-between attacks as well as across attack phases.

DISCLOSURES

Acaster Lloyd were commissioned by Ionis Pharmaceuticals to undertake this study. KG, GS, MG are employees of Acaster Lloyd. SA is company director and employee of Acaster Lloyd and holds shares in the company. AZ is an employee of Biopoint Pharmaceutical and Biotech Consulting and may hold shares in the company. MVL is an employee of Ionis Akcea and may hold shares in the company.

REFERENCES

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