

Women's Experiences of Living with Hereditary Angioedema: A Secondary Qualitative Analysis

Hereditary Angioedema (HAE) is a rare inherited disorder that causes potentially life-threatening episodes of swelling.¹ For many women, hormonal factors can worsen symptoms, adding complexity to managing the condition.² While previous research has focused on diagnostic challenges and clinical management of HAE,³ limited attention has been paid to how women navigate the condition within the context of their gendered roles and specific health needs. This study explores women's experiences of living with HAE, focusing on how gendered roles, health needs, and social contexts influence symptom management, care experiences, and daily life.



Design: The study presents findings from a secondary qualitative analysis of interview and qualitative survey data

Methods: Reflexive Thematic Analysis.

Demographics: The analysis included 42 women aged 22–76 years, capturing experiences across key reproductive transitions and later life stages.

Two overarching themes captured women's gendered and maternal experiences of HAE. "It's Not Just Hormones: Biology as Burden, Bias as Barrier" showed how reproductive life events triggered symptoms while systemic gendered bias led to dismissal and diagnostic injustice. "Motherhood Under the Weight of Illness" highlighted the emotional burden of genetic guilt, the medicalisation of pregnancy, and the hidden strains of caregiving. Together, these themes reveal how HAE profoundly shaped women's identities, relationships, and healthcare experiences.

It's Not Just Hormones. Biology as Burden, Bias as Barrier

Subtheme 1: Hormonal and Reproductive Life Events as Symptom Triggers

- Many women described hormonal milestones (puberty, menstruation, pregnancy, menopause) as intensifying HAE symptoms.
- For some, reproductive transitions created unpredictability, disrupting daily life and bodily autonomy.
- Female biology was often experienced as a source of instability, constraint, and anticipatory anxiety.
- Several women described these life stages as biographically disruptive due to illness unpredictability.

"there was never any real illnesses, if you like, until I started taking the pill."

Subtheme 2: Medical Dismissal and Diagnostic Injustice in Women's Health

- Some women reported that symptoms were misattributed to hormones, stress, or anxiety.
- Many described prolonged diagnostic delays and disbelief from professionals.
- For several participants, self-advocacy was required to achieve an accurate diagnosis.
- Gendered bias in healthcare often compounded emotional distress.
- A number of women lost trust in healthcare professionals, feeling discredited and ignored.

"And then they thought that I was making myself ill, so I was told it was psychological"

Motherhood Under the Weight of Illness

Subtheme 1: Emotional Burden of Maternal Guilt and Genetic Responsibility

- Some mothers described feeling deep guilt about potentially passing HAE to children.
- Anticipatory grief and fear of causing suffering were common for several women.
- A number experienced tension between ideals of maternal protection and risk of transmission.
- This emotional burden shaped self-perceptions as both patients and parents.
- Women sometimes internalised hereditary responsibility.

"If I had known about my condition, if I had more knowledge, I think I would never have had a child."

Subtheme 2: The Medicalisation of Motherhood and Loss of Normal Reproductive Experience

- Pregnancy and childbirth were often highly medicalised due to clinical risk.
- Some women felt reduced to "patients" rather than empowered mothers.
- Preferences around birth were sometimes overridden by illness management.
- Several women described emotional detachment and loss of control.
- These accounts exposed a gap in compassionate, coordinated maternity care.

"But literally, as I was crowning, I was getting IV Berinert bolused into one of my veins, rather than pain relief."

Subtheme 3: Strained Motherhood and Invisible Illness

- Many women spoke about juggling unpredictable symptoms with constant caregiving.
- Some described concealing pain to protect children and maintain normality.
- Women often felt pressure to "push through" with limited recognition or support.
- Illness invisibility sometimes fostered isolation, exhaustion, and stigma.
- For several women, motherhood became a site of resilience but also an unacknowledged burden.

"I wanted to enjoy being away on holiday and doing our things...even if you don't look very unwell, you can still feel really miserable underneath".



Implications for Practice

- Incorporate hormonal life stages into HAE care and symptom planning.
- Address gendered diagnostic delays through training and awareness.
- Provide emotional support for mothers facing hereditary transmission.
- Ensure personalised, coordinated maternity care for women with HAE.
- Recognise the hidden burden of invisible illness in caregiving roles.
- Use a biopsychosocial approach to support identity, emotion, and wellbeing.

Conclusions

Women with HAE often face unique challenges shaped by hormonal, familial, and societal roles. Greater awareness and gender-sensitive support are needed to improve care and patient wellbeing.

References

1. Lumry, W. R., & Settipane, R. A. (2020). Hereditary angioedema: Epidemiology and burden of disease. *Allergy & Asthma Proceedings*, 41(Suppl 1), S8–S13. <https://doi.org/10.2500/aap.2020.41.200050>
2. Kulkarni, M., Travers, J. B., & Rohan, C. (2021). High estrogen states in hereditary angioedema: A spectrum. *Clinical Reviews in Allergy & Immunology*, 60(3), 396–403. <https://doi.org/10.1007/s12016-020-08800-8>
3. Grumach, A. S., Gadir, N., Kessel, A., Yegin, A., Martinez-Saguer, I., & Bernstein, J. A. (2023). Current challenges and future opportunities in patient-focused management of hereditary angioedema: A narrative review. *Clinical and Translational Allergy*, 13(5), e12243. <https://doi.org/10.1002/ctt2.12243>

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