



Exploring Patient Experiences of Using Long-term Prophylaxis for the Management of Hereditary Angioedema

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BACKGROUND

- Hereditary Angioedema (HAE) is a rare inherited disorder causing recurrent, painful swelling in various body parts (1). These episodes can disrupt daily life- affecting work, education, mental health, and quality of life (2,3,4).
- Effective disease management, including prophylactic treatment, is essential. However, patient experiences beyond clinical outcomes are underexplored
- Clinical trials (e.g., lanadelumab and C1-INH) report improved quality of life and general health (5, 6). Yet, how patients experience these treatments in day-to-day life is less understood.
- UK study: Found treatment barriers and psychological challenges (7). US study: Reported reduced anxiety and improved functioning with C1-INH (8). These findings show the importance of combining clinical data with patient perspectives.
- This qualitative study explores how patients experience long-term prophylaxis, focusing on perceived benefits, fears, practicality and challenges. **Research question: How do patients experience using long-term prophylaxis for the management of hereditary angioedema?**

METHOD Design

- Qualitative design using online semi-structured interviews, analysed with reflective thematic analysis (9).

Participants

- Fourteen adults (7 male, 7 female) living with HAE and prescribed prophylaxis were recruited via purposive sampling through HAE UK. Most identified as White (93%), with one participant identifying as Asian.

Materials

- A semi-structured interview guide was used flexibly to explore participants' experiences with HAE and its treatment.

Procedure

- Informed consent was obtained, and participants completed a demographic questionnaire on Qualtrics before an online interview via Microsoft Teams. They received a £20 gift voucher for their time and were debriefed.
- Ethical approval was granted by Staffordshire University's Ethics Committee, and the study adhered to the BPS Code of (2021).

FINDINGS

Three themes were developed relating to patient experiences of using LTP for HAE: treatment availability and accessibility, facilitators and barriers to adherence and the individual healthcare system interface.



Treatment availability and accessibility: *"I was stressing because I had no medication- what if I had a flare up?"*

Despite advancements in treatment options, UK access remained inconsistent due to systemic and geographic factors, supply chain delays, prescribing criteria, self-administration ability, and varying support from HCPs and the NHS.

Facilitators and barriers to adherence: *"It's difficult to find time and space..."*

Participants shared varied and unique experiences around following their LTP treatment regime. The experiences highlight the complexity of adherence which is influenced by various factors including: individual characteristics, lifestyle, practicality and support networks, including the healthcare infrastructure, either facilitating or hindering consistent LTP use.

The individual healthcare system interface: *"I know I could get the care if I needed it..."*

This theme explores how individuals experience, navigate and are treated by the healthcare system while using LTP. **Subtheme 1: Navigating Systems:** *'there can be a lack of coordination between the consultant and the GP.'* Participant accounts reflected generally patient-centred care, but highlighted systemic issues, particularly poor continuity, coordination, and communication between primary and secondary care, leading to prescription delays. **Subtheme 2: Relational Care :** *'it was always a discussion'* Many participants emphasised the value of continuity of care in managing HAE, enabling informed decisions, adaptive approaches, and more personalised care.

CONCLUSIONS

- This study explored patient experiences with long-term prophylaxis (LTP) for managing hereditary angioedema (HAE).
- Despite advancements in treatment and increased drug options, systemic barriers continue to limit access.
- Both individual and structural factors affect consistent treatment use.
- Improving access is essential, as autonomy, accessibility, and control are key to effective HAE management.
- Participants valued strong relationships with specialists, which supported collaborative decision-making.
- Proactive, patient-centred approaches should be continually adopted to improve HAE care and outcomes.

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