Healthcare professional perceptions and experiences of working with patients with Hereditary Angioedema

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BACKGROUND

Hereditary Angioedema (HAE) is a rare genetic condition causing non-itchy, often painful and distressing swellings, including potentially life-threatening throat attacks (1). Prevalence is estimated at 1 in 50,000–150,000 (2).

Awareness of HAE is limited, particularly in non-specialist settings like emergency departments (3), contributing to diagnostic delays and inconsistent care. Although early diagnosis is improving, many patients still face long delays (4).

HAE management is complex, requiring personalised care plans due to variation in symptoms and disease burden (5). Clinicians in specialist services are well-placed to reflect on these challenges and offer insights into improving diagnosis and ongoing care.

Research questions: a) What do healthcare professionals supporting HAE patients think about working with these patients? **b)** What do healthcare professionals supporting HAE patients think are the biggest barriers to diagnosis for patients? **c)** What do professionals supporting HAE patients think about how HAE patients engage with disease management recommendations?

METHOD

- Qualitative design
- Five healthcare professionals working within HAE clinics. Online individual semi-structured interviews analysed using reflective thematic analysis (6).
- Informed consent was obtained, and participants completed a demographic questionnaire on Qualtrics before an online interview via Microsoft Teams. They received a 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

Meaningful Relationships and Professional Fulfilment in HAE Care

Healthcare professionals described deep personal and professional satisfaction in working with HAE patients. Long-term, family-based relationships allow trust and continuity, while advances in treatment have made care more optimistic and effective. Clinicians expressed appreciation towards how defined, specific and straightforward HAE is as a condition despite its rarity, and felt rewarded seeing patients improve, take control, and experience better quality of life.

"The most enjoyable thing has been just to see over the years, the developments from science that have come into practice and how they've changed the lives of patients." (Consultant Immunologist)

Systemic and Diagnostic Challenges

Delayed diagnosis is common due to limited awareness of HAE in general and primary care, especially when there is no known family history. Diagnosis is often driven by patients or families with prior experience. Clinicians face frustration coordinating care with non-specialist teams and advocating for patients. System-level gaps and inconsistent recognition make the diagnostic process fragile and emotionally taxing for both patients and professionals.

"Their parents went to the GP, saying I have this diagnosis, this syndrome and they weren't referred and I picked it up by accident [...] I think it's complete lack of awareness of what the disease entails, who to refer to?" (Consultant in Paediatric Immunology)

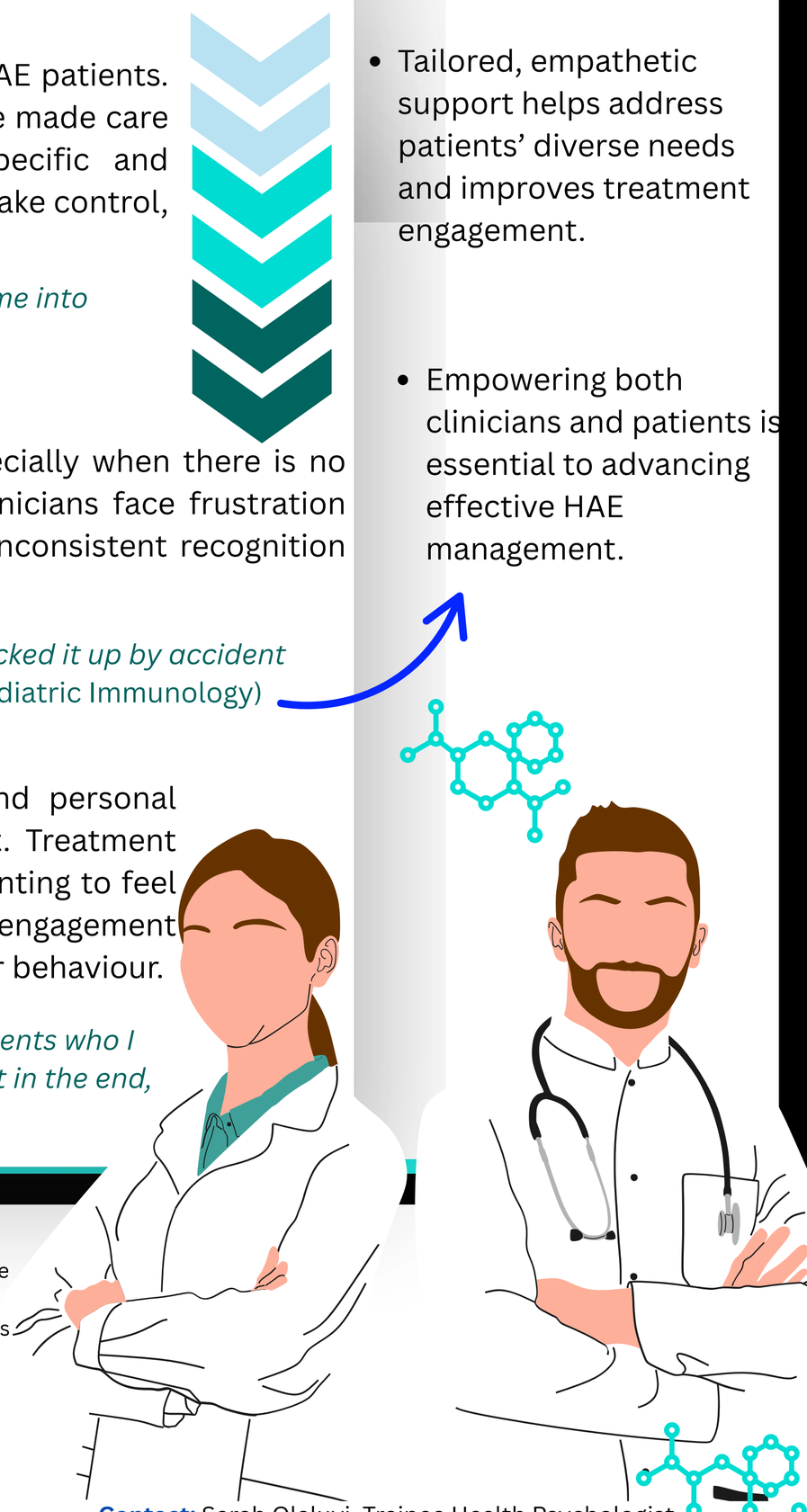
Navigating the Patient Journey and Engagement

HAE affects patients uniquely, influenced by their experiences before diagnosis, emotions, and personal situations. Some face difficulties accepting the condition, worry about passing it on, or deny it. Treatment engagement varies; adolescents may resist care, while others delay treatment due to anxiety or wanting to feel normal. Professionals provide empathetic, personalised support, often led by nurses, to improve engagement and help patients manage their condition but sometimes feel powerless to help patients change their behaviour.

"They're all adults. So, there's very little you can do. You can't go complaining to their mum [...] I've had patients who I have tried and tried to speak to and tell them that, you know, you have to take your medication regularly, but in the end, at the end of the day, if they don't want to, what can I do?"(Consultant Immunologist)

5 CONCLUSIONS

- Healthcare professionals find working with HAE patients rewarding but face challenges from limited awareness and systemic barriers.
- Improving education in general healthcare can reduce diagnostic delays and misdiagnoses.
- Better coordination between specialist and non-specialist services is needed to enhance patient care.
- Tailored, empathetic support helps address patients' diverse needs and improves treatment engagement.
- Empowering both clinicians and patients is essential to advancing effective HAE management.



REFERENCES:

1. Longhurst HJ, Farkas H, Craig T, Aygören-Pürsün E, Bethune C, Bjorkander J, et al. HAE international home therapy consensus document. Allergy Asthma Clin Immunol. 2010;6(1):22.
2. Lumry WR, Settipane RA. Hereditary angioedema: Epidemiology and burden of disease. Allergy Asthma Proc. 2020;41(Suppl 1):S08–S13. https://doi.org/10.2500/aap.2020.41.200050
3. Burton AE, Lindsay-Wiles I, Herron D, Owen A, Elliott J, Metcalfe A, et al. Hereditary angioedema patient experiences of medication use and emergency care. Int Emerg Nurs. 2023;71:101339. https://doi.org/10.1016/j.ienj.2023.101339
4. Zanichelli A, Cristina GMA, Vacchini R, Caballero T. Safety, effectiveness, and impact on quality of life of self-administration with plasma-derived nanofiltered C1 inhibitor (Berinert®) in patients with hereditary angioedema: the SABHA study. Orphanet J Rare Dis. 2018;13(1). https://doi.org/10.1186/s13023-018-0797-3
5. Paige D, Maina N, Anderson JT. Hereditary angioedema: Comprehensive management plans and patient support. Allergy Asthma Proc. 2020 Nov;41(Suppl 1).
6. Braun V, Clarke V. Thematic analysis: A practical guide. London: SAGE Publications; 2022.

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