



University of  
Staffordshire

# **The power and impact of qualitative methods: A case study on Hereditary Angioedema**

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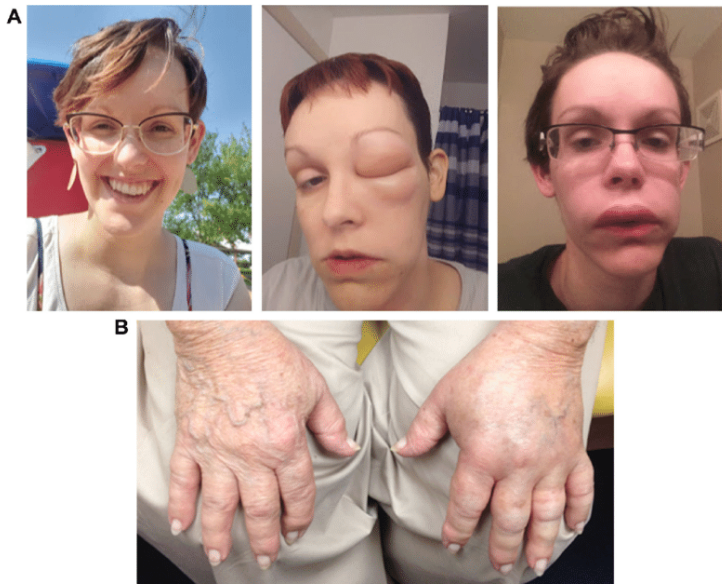
**QMIP Conference, July 2025, Leeds**

# Talk overview

- ↓ What HAE is: a short introduction
- ↓ Where our research into HAE began
- ↓ Where our research into HAE went next
- ↓ Where our research into HAE is going in the future



# WHAT IS HAE?



- HAE is a rare genetic autosomal dominant disorder
- If a parent has HAE there is a 50% chance, they will pass it on to their children.
- HAE causes swelling of the tissues (angioedema)
  - Can last up to 5 days
  - Can occur in any part of the body
- In the most severe cases (airway swellings) there is an urgent need for medical attention as swelling can cause death by asphyxiation.

Image from: Manning ME. Recognition and Management of Hereditary Angioedema: Best Practices for Dermatologists. *Dermatol Ther (Heidelb)*. 2021 Oct;11(5):1829-1838. doi: 10.1007/s13555-021-00593-x. Epub 2021 Aug 30.

# DIAGNOSIS



- Diagnosis can take 4-9 years (however, this is largely dependent on the country).
- The average undiagnosed period in HAE is longer than in many other rare diseases.
- HAE is often misdiagnosed leading to unnecessary treatments and medical procedures.
- Early diagnosis of HAE is essential. Mortality is estimated to be three times higher in patients who are undiagnosed than in those who are diagnosed.

Isono, M., Kokado, M., & Kato, K. (2022). Why does it take so long for rare disease patients to get an accurate diagnosis?—a qualitative investigation of patient experiences of hereditary angioedema. PLoS One, 17(3), e0265847

# HOW HAE IS TREATED



## **On demand (or rescue) medication**

- Aims to treat acute angioedema attacks to reduce severity and duration

## **Long-term prophylaxis (preventative or maintenance therapy)**

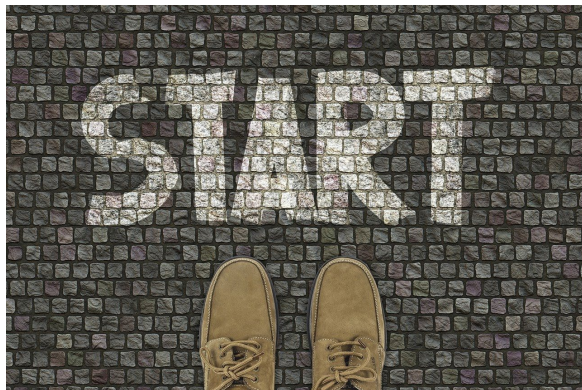
- Used on a regular basis to prevent angioedema attack- taken daily, weekly or monthly depending on attack frequency. Administered by IV, or sub cutaneous injections or oral medications.

## **Short-term prophylaxis**

- Used when patients anticipate exposure to a known or potential attack trigger to reduce the risk of attacks



# WHERE OUR RESEARCH BEGAN...



HAEUK.org

- In 2021 we were contacted by Dr Lavanya Diwakar a consultant immunologist at the University of North Midlands NHS Trust.
- Dr Diwakar wanted to know more about the life experiences of patients living with HAE to improve HAE care and support.
- We sought funding from HAE UK which is a patient and carer support charity.
- Together we designed a mixed methods study.

# THE INITIAL STUDY



## Quantitative

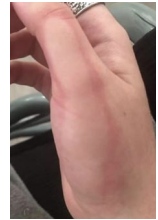
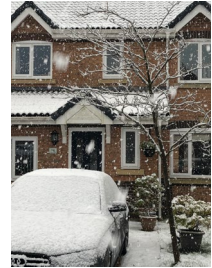
- Online survey including a range of questionnaires measuring:
  - Illness representations
  - Coping
  - Wellbeing
  - Quality of life
  - Demographics
  - HAE questions

Analysed with multiple regression  
**[Paper coming soon....]**

## Qualitative

1. Open-text qualitative survey questions as part of the online survey.
2. In-depth, semi-structured photo-elicitation interviews with a self-selected subsample of survey respondents.

Analysed with Reflexive Thematic Analysis (Braun & Clarke, 2022)



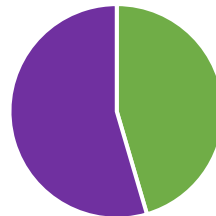
# PARTICIPANTS

**Survey**  
**(n=65)**

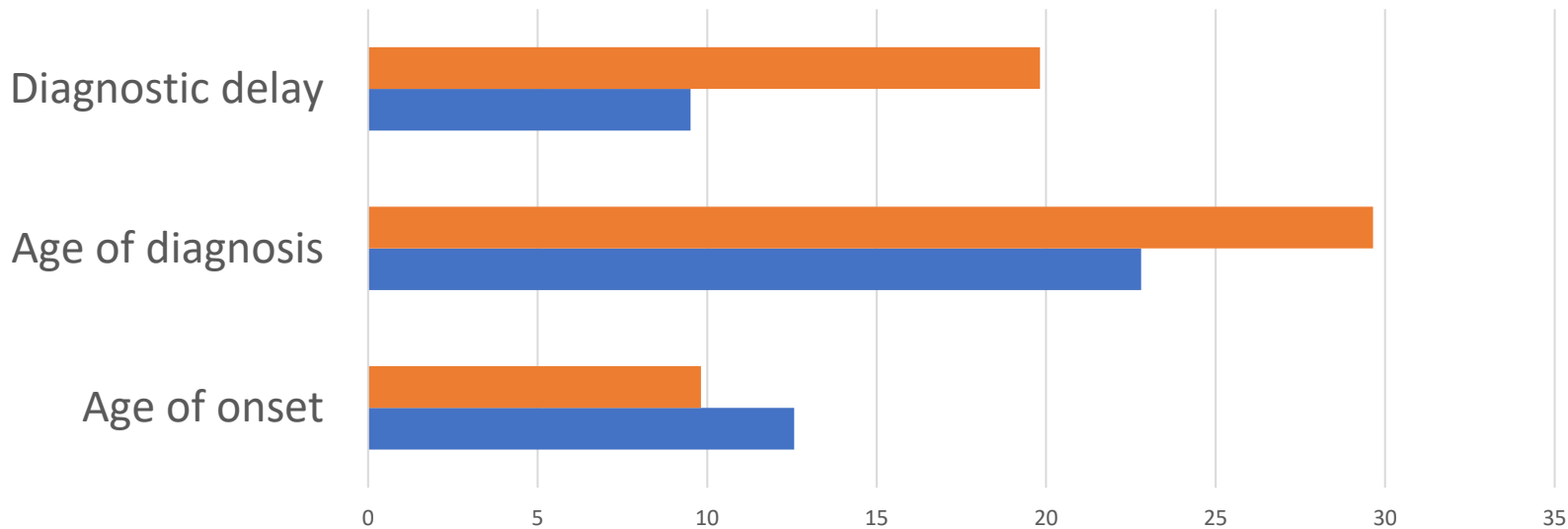


■ Male ■ Female

**Interview**  
**(n=11)**



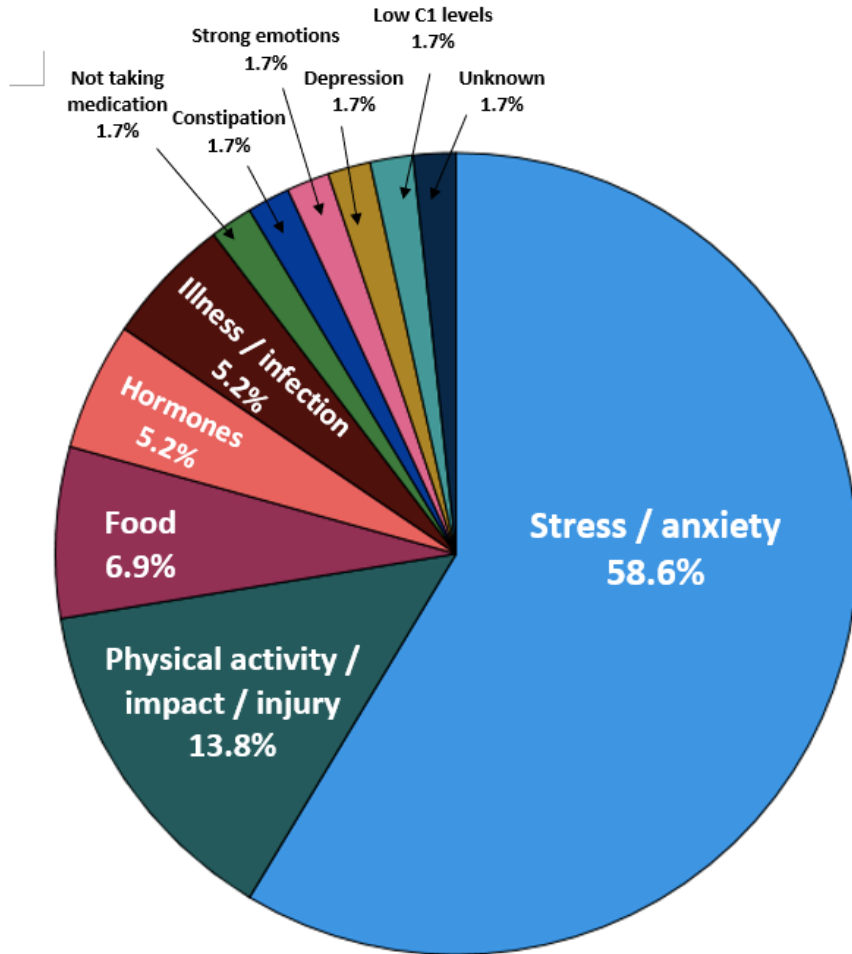
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# WHAT DO PEOPLE WITH HAE PERCEIVE TO BE THE MOST COMMON TRIGGER FOR THEIR ATTACKS?



# QUALITATIVE FINDINGS



## Feeling alone

*Nobody understands this condition. And even my husband, and he's seen me at my absolute worst with it . . . [...] I say to him, I'd just quite like you to have this just for one day, just for one attack so that you can see what it's like. And he says 'why would you wish that on anybody?' (laughs) 'I don't really wish you to have it, but just so that you can understand what it is that I'm going through'. Yeah, it can be quite lonely. (Sophie)*

## Family planning

*The only thing, I was really worried for my daughter not to get it. And she didn't get it, thank God . . . this what worries me, this why for eight years I didn't have a baby, I didn't have children.... Cause I did want to, I said no I'm not going to give it to somebody else.... (Rosanna)*

## The value of acceptance

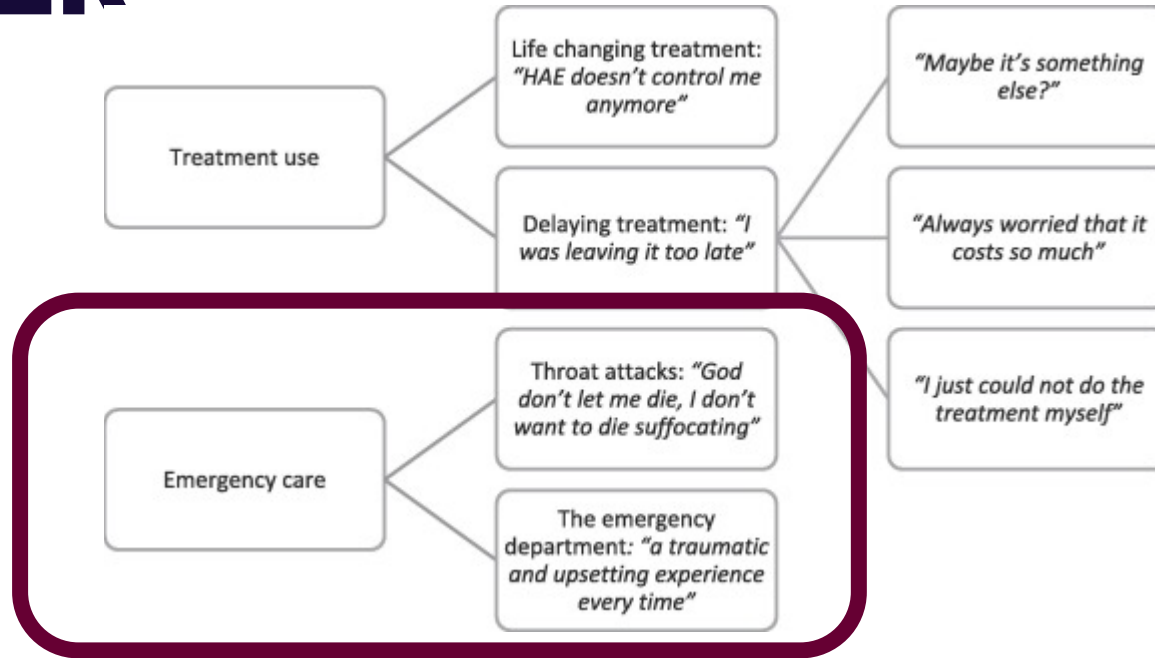
*HAE requires a lot of patience and acceptance, but if you find it in you to accept the reality, then things get much easier, despite the evident physical limitations of the condition. (Callum) [Paper... coming soon]*

Fear of throat attacks

Life changing treatment

Psychological triggers

# TREATMENT AND EMERGENCY CARE PAPER



# EMERGENCY CARE



All I was thinking was 'oh God don't let me die, I don't wanna die suffocating, being aware I'm suffocating'... and I remember them coming and saying 'if it doesn't start going down, we're gonna have to sedate you and incubate [sic] you', and all I wrote on this pad was 'please don't let me die', that was my only thought in my head was '**please don't let me die**'. (Maria, 51, F, Interview)

[My most severe HAE episode was] sudden onset of severe facial swelling, extending below jaw line. Feeling of panic as soft tissue in throat affected. Attended A&E, **treated as a domestic violence victim** and husband subjected to critical interview at triage before the situation treated seriously. (Elizabeth, 61, F, Survey)

Staff don't understand HAE and can be heard googling it and discussing it in the corridor. Don't have medication in hospital pharmacy, or if night-time it is locked up. Can only get icatibant sent over from [another hospital] by taxi (icatibant doesn't work for me and gives severe and prolonged skin reaction). Left in waiting room for hours. [...]. **A traumatic and upsetting experience every time.** (Emma, 46, F, Survey)

# HOW DID THESE FINDINGS HAVE IMPACT?



- We created an educational video.
- The video is designed to raise awareness in Emergency Department staff of what to do if they encounter a patient with HAE.
- It was developed using Health Psychology behaviour change theory to target capability, opportunity and motivation which are the key determinants of behaviour ([Michie et al. 2011](#))
- We included voices of patients, specialist immunologists, and charity representatives
- We are now disseminating and evaluating the effectiveness of the video through more research!

# HAE VIDEO FOR CLINICIANS





# TRAINEE HEALTH PSYCHOLOGIST

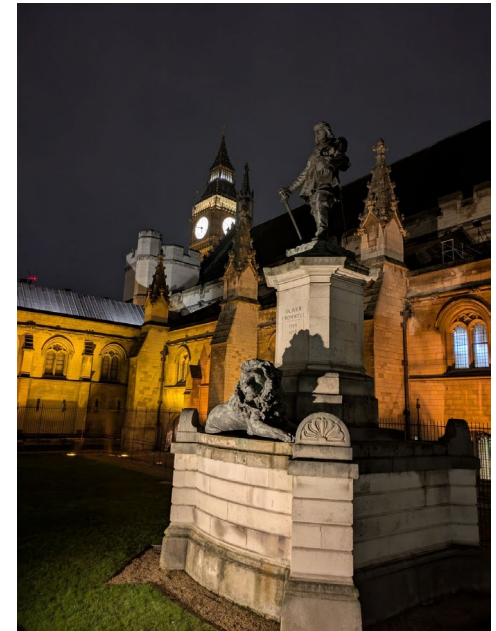


- HAE UK funded a University of Staffordshire studentship for the completion of the Professional Doctorate in Health Psychology with a focus on HAE.
- So far Sarah Olaluyi has:
  - **Completed a systematic review** on the social and psychological impacts of HAE and presented this as part of an educational webinar for immunologists and other healthcare professionals.
  - **Delivered a range of teaching sessions** to students and healthcare professionals to raise awareness of HAE.
  - **Networked at a HAE UK patient day**, meeting lots of patients and healthcare professionals.
  - **Completed a qualitative study with 14 participants** exploring the experience of long-term prophylaxis.



# ONGOING IMPACT

- We are working on a qualitative project (engaging two MSc students as research assistants) interviewing immunologists and other healthcare professionals to better understand:
  - Routes and barriers to diagnosis
  - Perceptions of facilitators and barriers to HAE management
- We attended a parliamentary reception at the house of commons where we helped to advocate for improved support for patients with HAE including the need to:
  - Improve awareness of HAE in Emergency Departments
  - Develop and improve access to psychological support for those with HAE
  - Ensure all patients with HAE get access to the most appropriate treatment to manage symptoms and enhance quality of life.



# MORE IMPACT COMING SOON...

- Training for healthcare professionals on “how to talk so your patients will listen”
- Informed by our qualitative studies with patients and clinicians



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## Psychology and HAE: How to talk so that your patients will listen

### WE ALSO KNOW THAT PATIENTS DON'T ALWAYS FOLLOW MEDICAL ADVICE...

I just take [on-demand medication] when it's extreme, probably... absolute extreme – my face, my throat, whatever. Otherwise, I don't take it (Rosanna, 74, F, Interview)

I was leaving [on-demand medication] too late and putting it off just thinking “oh, it's not an attack” and tricking myself, even though I knew the pain was bad. (Ben, 30, M, Interview)

My son-in-law has got so used to giving [injections] to his wife that he gave me one once. [...] I don't [self-administer], I've never had to cause there's always been somebody else to do it. (Carolyn, 76, F, Interview)

Examples from: Burton AJ, Lindsay-Whiles L, Herron D, Owen A, Elliott L, Metcalfe A, Dewaker L. Hereditary Angioedema patient experiences of medication use and emergency care. *Int Emerg Nurs*. 2023 Nov;71:103339. doi: 10.1016/j.ien.2023.101339. Epub 2023 Sep 14; PMID: 37733940.

### AND SOME CLINICIANS FEEL POWERLESS TO CHANGE PATIENT BEHAVIOUR...

They're all adults. So, there's 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)

[A Mum of one of my patients told me she was regularly having swellings] I said, “did you not have your, do you not take your prophylaxis?” She goes “no, I just thought it'd go away” [Laughs] [...] I said to her “tell your consultants about all these attacks” because she wasn't doing. She wasn't telling them she wasn't treating them. She wasn't getting through prescriptions, so no one knew. (Consultant in Paediatric Immunology)

Examples from: Burton et al (Work in progress, publication forthcoming). Interviews with Healthcare Professionals working with patients with Hereditary Angioedema.

### THERE ARE SOME TOOLS YOU CAN USE TO HELP GUIDE YOUR PATIENTS TOWARDS CHANGING THEIR BEHAVIOURS

### WHY REFLECT “CHANGE TALK”?

We can think about readiness for change as a continuum

The more someone talks about change and how this could be achieved the further along this continuum they move

It is possible to shift people along the continuum by eliciting change talk

Prochaska and DiClemente (1983):  
Stages of Change Model

Precontemplation	No	I will not...
Contemplation	Maybe	I could...
Preparation	Prepare	I intend to...
Action	Do	I will...
Maintenance	Keep Going	I do...

### KEY SKILLS FOR CHANGE TALK DISCUSSIONS...

**O** pen-ended questions

**A** affirming responses

**R** effective listening

**S** ummary statements

How would you like things to be different?  
What have you tried before?

I appreciate that you are willing to share ... x  
I can see you've already tried very hard

So, it sounds like... (reflect the change talk)

Here is what I've heard, tell me if I missed anything?  
What will be your first step?

# ANY QUESTIONS?

## Contact Details

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**HAE UK:** [www.haeuk.org](http://www.haeuk.org)

**Other collaborators:** Dr Lavanya Diwakar, Dr Alison Owen, Dr Dan Heron, Dr Jade Elliott, Isabelle Lindsay-Wiles, Mila Krajewska.

**Learn more about Dr Amy Burton's HAE and other research here or scan the QR:**

<https://tinyurl.com/4rdspu23>

