

**“If We Had Blood Pouring Out of Our Eyeballs, People Would Notice”; a Qualitative Exploration into the Psychological Experience of Cluster Headache”.**

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## Background

Cluster Headache (CH), is known as one of the most painful conditions a human can experience. The condition involves painful ‘attacks’ which last between minutes and a few hours, and then pain-free periods. See visual depiction of the pain from a sufferer (OUCH, 2024).



There are two types of CH: 1) Episodic (involves ‘bouts’ of attacks and then a period of remission lasting at least 3 months) and 2) Chronic (no significant remission period).

The condition has been associated with poor quality of life, and psychopathology. Current NICE guidelines (NICE, 2022) all relate to medical interventions (medication, surgery, high flow oxygen). These interventions are limited in effectiveness, come with side effects, and do not target the psycho-social impact of the condition (Grinberg, 2021). Lack of guidelines related to psychological support is likely due to lack of research focused on the psychological experience of CH. This thesis portfolio aimed to fill this gap.

>**RQ1:** What psychological aspects are important in the experience of an acute Cluster Headache attack?

>**RQ2:** What psychological aspects are important in the experience of Cluster Headache between attacks?

## Methods

**Design:** Qualitative semi-structured interviews. Reflective Thematic Analysis was conducted with a critical realist lens.

**Patient and Public Involvement (PPI):** The research topic was proposed by an individual who has Chronic CH. They were involved throughout the research process and attended all meetings.

**Participants:** 13 participants with either chronic or episodic CH were recruited through opportunity sampling; the study was advertised on the website of the UK Cluster Headache charity (OUCH).

**Materials:** An interview topic guide was produced by the research team (including the PPI representative) and OUCH.

**Procedure:** Interviews occurred via Microsoft Teams or telephone.

**Data Analysis:** Braun and Clarke’s (2022) 6-step method was applied to the interview transcript. NVivo14 was used for coding.

## Results

Theme (Sub-themes)	Example Quote
<b>Darkness</b> (Evil Phenomenon) (Dark Cognitions)	“It’s like it’s out to get ya. Like it’s coming for you. You know that expression, the dark night of the soul?”
<b>Battling</b> (With the Pain) (For Recognition)	“It’s the visual representation. If we had blood pouring out of our eyeballs, people would notice”
<b>Shifting Between Being in and Out of Pain</b>	“I can be absolutely fine one minute, talking to you normally, and then suddenly bang I’ll be in absolute agony. Which is really difficult because people seem to think you’re making it up”.
<b>Control</b> (Knowledge) (Planning)	“When they first started I was very concerned and thought I was probably having a brain tumour. Once I started seeing specialists, they were very reassuring and over the years I’ve gotten to accept it is what it is”.
<b>Despair</b>	“You don’t see light at the end of the tunnel”.

## Key Findings

- The psychological experience of living with CH is complex.
- Factors which influence the themes and the experience of living with CH included: 1) whether individuals were in the moment of the attack of pain, or in-between attacks, 2) the type of CH (chronic or episodic), 3) the length of time participants had lived with CH.
- Once sufferers became familiar with CH, their psychological response changed, and their distress often reduced. Participants reported trying to relax through the pain, not avoiding social events, reduced negative thoughts about CH, and feeling more in control through knowledge and planning.
- Individuals with Chronic CH reported a more difficult experience, due to lack of respite from the pain.
- Lack of awareness from healthcare professionals and the public exacerbated distress. Diagnosis took a long time, and the public compared the pain to migraines due to the name cluster “headache”. Participants felt the name undermined the severity of CH.

### Clinical Implications:

- There is a need for increased visibility of CH.
- Future research should explore whether psychological interventions could be developed which support CH individuals to live a fulfilling life alongside their condition.
- Research should consider exploring chronic CH independently.
- The PPI representative ensured the thesis portfolio was focused on a meaningful topic, and that the work met the needs of the CH community. Future research should consider whether PPI involvement throughout should become routine.