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Research Article

"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: The primary headache disorder, cluster headache (CH), is known as one of the most painful conditions a human can experience. This study aimed to explore the psychological experience of living with CH, both during acute headache attacks and between attacks.
Methods: Semistructured interviews were conducted with 13 adults with episodic or chronic CH. Interviews were carried out via Microsoft Teams or the telephone. Qualitative interview data were analysed using Reflective Thematic Analysis (RTA) through a critical realist lens. Participants also completed the Pain Self-Efficacy Questionnaire and Pain Catastrophising Scale.
Results: RTA resulted in five themes emerging related to the psychological experience of CH: "Darkness," "Battling," "Shifting," "Control," and "Despair." Psychological experiences during the acute attack appeared distinct from experiences of the condition between attacks. The psychological experience was impacted by how long participants had lived with the condition and by whether they had the episodic or chronic form. Individuals living with the chronic form of CH reported increased despair and depression, due to lack of respite from the pain. In contrast, individuals living with episodic CH were less despairing due to pain-free periods but talked to increased uncertainty, with it being unclear when the painful bout would disrupt their life.
Conclusion: Living with CH is a complex and challenging psychological experience. Further research to identify how psychological processes may maintain distress and exacerbate pain could help establish a psychological model of CH. Such a model could, in turn, enable exploration of psychological techniques to support individuals during and between CH attacks. Authors also call for research to explore how to increase visibility of CH.

Keywords: cluster headache; patient and public involvement; reflexive thematic analysis

1. Introduction

Headache disorders are under-recognised and undertreated [1]. Cluster headache (CH) is a severe primary headache disorder [2]. A primary headache disorder means it is not caused by, or a symptom of, another illness. Other primary headache disorders include tension-type headache (TTH) and migraine [2]. CH is relatively rare, with lifetime prevalence being reported as 0.12% of the global population [3, 4]. The rarity of the condition means it is not well known amongst clinicians, and diagnosis is often missed or delayed [5]. However, it is commonly seen in clinical specialist headache centres and is cited as one of the most painful conditions known to humankind [6–8]. The condition involves unilateral severe pain which occurs in "attacks" which last between five and 180 min and then pain-free periods [2].

CH is categorised into two forms based on frequency of the attacks [2]. The more common (85%–90% of sufferers) "episodic" form (ECH) involves bout periods (weeks or months), when one has frequent attacks. ECH sufferers then have periods of pain-free remission which are at least 3 months in length. The less common "chronic" form (CCH;

10%–15% of sufferers) is characterised by attacks occurring for at least a year, with no significant remission period (less than 3 months). The peak age of onset is between 20 and 40 years, and it is reported to be around three times more common in men than women, which sets it apart from migraine and TTH which are more common in women [9].

CH has been associated with suicidality, reduced quality of life, depression and anxiety [10, 11]. Despite these associated psychological aspects, National Institute for Health and Care Excellence (NICE) guidelines for treatment in the United Kingdom (UK) are all related to medical interventions, which are limited in effectiveness, and individuals with CH are rarely offered mental health support [12, 13].

Lack of treatment guidelines for CH focused on psychological approaches likely stems from a lack of related research, as NICE guidelines only advise when there is a strong evidence base [14]. The few studies which have explored psychobehavioural approaches to managing CH examined progressive muscle relaxation, bio-feedback and cognitive behavioural stress management [12, 15–18]. However, these studies were uncontrolled, had a small sample of CH participants and did not explore underlying processes of the treatment effect, if one was reported [12, 19]. To understand underlying processes of potential treatment, qualitative research is helpful to understand individual lived experience. Two previous qualitative interview studies in Spain [20] and the UK [21] have been conducted related to CH, focussing on the general experiences of living with the condition. Authors used phenomenological [20] and thematic [21] analysis to highlight that CH sufferers felt misunderstood and dominated by the headache, dreaded future attacks, were dissatisfied with pharmacological treatments and struggled to control the pain by any means.

The present study aimed to build on prior qualitative research by focussing specifically on the psychological experience of CH, i.e., the cognitive, affective and behavioural aspects. Whilst no research exists related to these factors regarding CH, a large body of literature demonstrates that pain is influenced by psychological factors [19, 22–25]. For example, low self-efficacy and pain catastrophising are two cognitive styles which have been related to worse pain management [26–28]. Behaviourally, both over and under exertion are associated with higher levels of pain [29]. Finally, in terms of affect, anxiety and depression have been shown to increase pain in a bidirectional manner [30].

The psychological focus of this research study was proposed by an individual who suffered from CCH and had no contact with mental health professionals throughout their five-year NHS treatment journey, despite feeling this was essential. The PPI representative was involved throughout the research process. The present study explored the psychological experience both during the acute attack and in the period between attacks. This decision was made in discussions with the PPI representative who noted how these phases are markedly distinct [3]. Authors hoped that the knowledge gained of the psychology of the CH sufferer would be a step towards understanding whether psychological treatments could support the CH community.

1.1. Research Question

1. What psychological aspects are important in the experience of an acute CH attack?
2. What psychological aspects are important in the experience of CH between attacks?

2. Methods

The study was reported in accordance with the Consolidated Criteria for Reporting Qualitative Studies (COREQ) 32-item checklist [31]. See File S1.

2.1. Design. This qualitative study involved semistructured interviews and Reflexive Thematic Analysis (RTA) to analyse interview data. Pain self-efficacy and catastrophising are often measured in pain management services, and so participants also completed two questionnaires measuring these concepts. These supporting data helped contextualise study participants.

2.2. Patient and Public Involvement (PPI). The PPI representative, who had chronic CH, attended every research meeting and was involved in decisions regarding study methods and data analysis. Whilst the PPI representative's opinions were considered crucial, the final decision resided with the traditional research team. The PPI level of involvement was therefore considered as "contribution" [32]. When reporting on PPI involvement, GRIPP 2 short form guidelines were followed [33]. See File S2.

2.3. Participants. To be included, individuals had to be over 18 years of age, living in the UK, English speaking and diagnosed with CH by a healthcare professional. Participants had to provide their general practitioner (GP) surgery contact details, due to the reported high rate of suicidal ideation amongst CH sufferers [34]. This allowed the researcher to follow up any active risk concerns by contacting the GP, which participants were made aware of before participating. Importantly, the research team, including the primary researcher who carried out the interviews, was qualified clinical psychologists, or trainee clinical psychologists. Therefore, they used their clinical expertise in assessing whether risk concerns needed to be addressed. All participants also received various support details in a debrief sheet. Individuals were excluded if they lived with comorbid facial or head pain.

Participants were recruited using opportunity sampling. The study was advertised on the webpage of the charity, Organisation for the Understanding of Cluster Headache [35]. Instead of recruiting a fixed sample size, the researchers conducted interviews until they determined that the interview data contained sufficient information power. This involved assessing how specific participants' characteristics were to the study aim and the quality of the dialogue [36]. Authors predicted responsible analysis would include around 15 participants, as this was in line with comparable previous studies, and so this number was initially sought

[36, 37]. A first-come-first-served approach was taken, with those who expressed interest first being screened. If individuals emailed after the required sample had been reached, they were informed by email that recruitment had finished.

2.4. Materials. A draft interview schedule was produced by the research team, which included the PPI representative and a clinical psychologist who previously worked in pain management services. Feedback was received and implemented, from OUCH. As shown in S3, the interview started with a "settling in question" to support the participant to feel at ease [38]. After this, there was a broad question about the research topic to facilitate the participant talking about their CH experience [39]. Questions then became more specific, enquiring about participants' thoughts, behaviours and feelings related to their pain. The topic guide asked specifically about experiences during the pain and outside of the painful attack, as these stages of the condition are distinct, and so separating allowed for deeper exploration of the unique psychological experience of each stage. This interview schedule was used flexibly, with the open-ended questions creating a dialogue which resulted in other questions emerging [40].

Participants also completed the psychometrically sound Pain Catastrophising Scale (PCS; [41]) and the Pain Self-Efficacy Questionnaire (PSEQ; [42]). For the PCS, high scores (> 30) indicate clinically significant levels of catastrophising [41], and for the PSEQ, low scores (< 20) indicate low self-efficacy [43].

2.5. Procedure. Individuals who contacted the primary researcher from the OUCH advertisement were emailed a study information sheet and initial consent form. If still interested, individuals were asked to email the researcher a completed initial consent form which gave permission for the researcher to telephone them. The researcher telephoned the consenting participants to discuss the research, determine suitability and collect demographic information. If eligible, participants were then given a final consent form to complete, and interviews were organised. Participants were given the choice of interviews being conducted on Microsoft Teams video, telephone or in-person. Semistructured interviews were conducted solely by the primary researcher, who was a trainee clinical psychologist completing a PhD, which included teaching on research methods. They were supported by a research team who had much experience with administering an interview schedule. After interviews, the researcher emailed over the questionnaires. After questionnaires were returned, the interviewer emailed a debrief form and a £10 Love2Shop voucher.

2.6. Data Analysis. RTA was used to analyse interview data, following the six-step approach created by Braun and Clarke: familiarisation of data, coding, generation of themes, reviewing themes, naming themes and writing up [44–47]. The audio recordings of the interviews were automatically transcribed by Microsoft Teams. The primary researcher reviewed and edited transcripts for accuracy to ensure verbatim accounts, which aided familiarisation. Participants were sent a copy of their transcript, and they were given 2 weeks to edit/redact/withdraw consent. One participant slightly edited their transcript by removing filler and repeated words. This new version was included.

Transcripts were transferred into NVivo14 for analysis [48]. The primary researcher actively listened to each recording again, whilst keeping analytic memos using the "memos" feature. Data were analysed inductively to allow the data to catalyse discovery. A critical realist lens was applied throughout RTA, meaning the researchers were reflective that their beliefs influenced their understanding of research findings [49–51]. A critical realist lens was helpful for this study, as this perspective values and acknowledges both the biological reality of the CH condition and the subjective psychological experience of individual sufferers. Salient thoughts/feelings experienced by the primary researcher were reflected upon in supervision. For example, when they felt particularly drawn to a quote or potential theme, they would discuss with the research team alternative interpretations and reasons for the salience. The primary researcher then went through each transcript line by line coding sections. All initial codes were extracted from NVivo14 into Microsoft Word where they were clustered together into groups of similar concepts/experiences by the research team. Themes/subthemes emerged and were then transferred back into NVivo14 and reviewed in relation to the whole dataset. After further reviewing and changing, five themes emerged.

2.7. Ethics. Approval was granted by the Faculty of Medicine and Health Sciences Ethics Committee at the University of East Anglia, after one set of amendments (ID: ETH2324-0070). Full written consent was obtained from all participants.

3. Results

3.1. Participants. Recruitment started in December 2023. There was significant interest in the study, with over 100 individuals responding to the advertisement. The first responding 15 participants were contacted, and 13 completed consent forms and so had interviews arranged. These interviews took place between January and April 2024. After the 13 interviews, it was determined that the data contained sufficient information power, so no further interviewees were sought.

Interviews took place by telephone ($N = 8$) or Microsoft Teams ($N = 5$). The mean length of the interview was 67 min (SD = 11.85 and range: 45–88) all occurred in one sitting, and only the interviewer and participant were present. The interviews were all long in length, due to participants' willingness and desire to share their personal experience. Therefore, often after

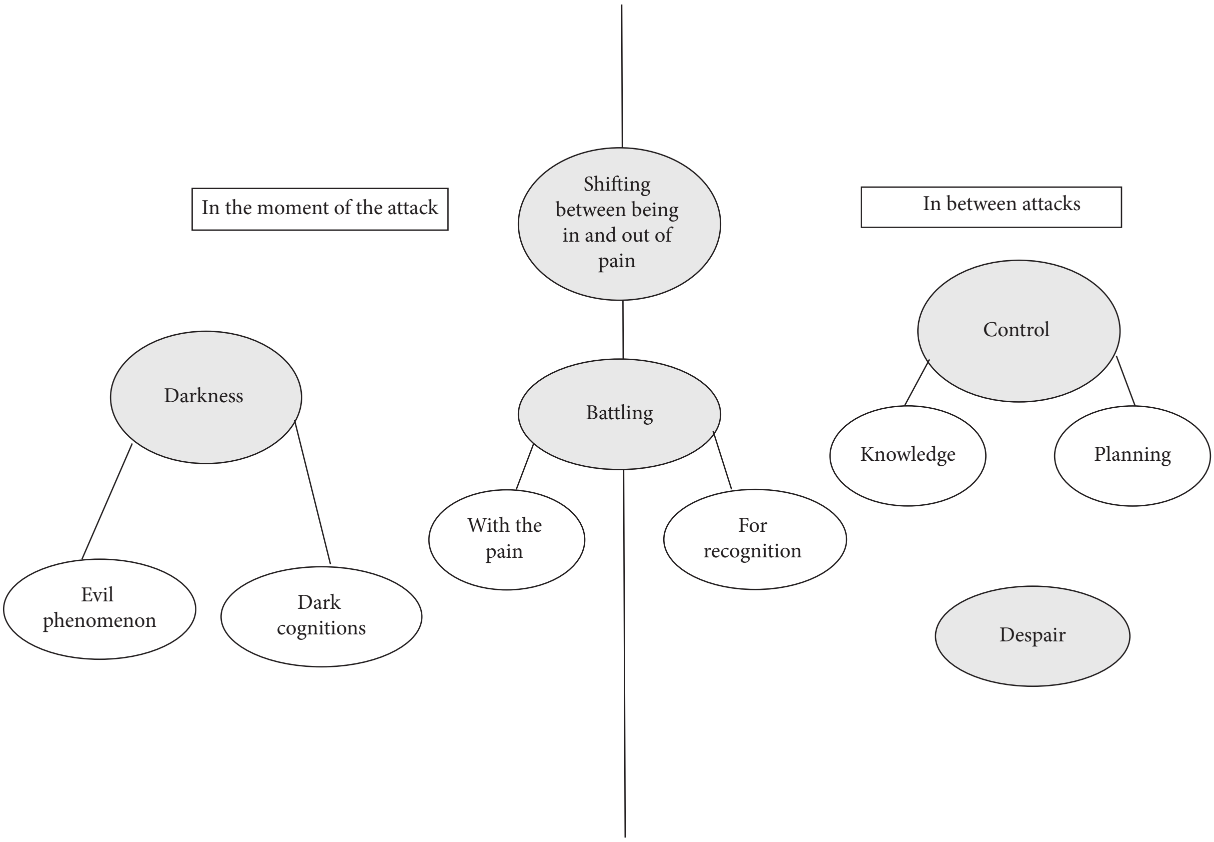

Figure 1: Thematic analysis map. *Note:* Grey circles are the main themes, and white circles are the subthemes.

being asked one question, participants would speak for several minutes. As the interview was semistructured, the interviewer would also ask relevant follow-up questions. Of the 13 included individuals, 69% were male, and nine had ECH and four CCH. The age of participants ranged from between 33 and 76 years old. Length of time living with CH ranged from 8 to 40 years.

3.2. Questionnaires. 11 out of the 13 participants completed the two questionnaires. It is unclear why two participants did not complete the questionnaire, with neither responding to several emails from the researcher. 64% of participants scored above the cut-off (> 30) for clinically significant pain catastrophising (mean score of 30.70 (SD = 11.54)). 72% of participants scored below the threshold (< 20) for low self-efficacy (mean score of 15 (SD = 16.49)), indicating the majority of participants had low self-belief in managing pain.

3.3. RTA. Five themes were identified in relation to psychological aspects of CH: (1) Darkness, (2) Battling, (3) Shifting, (4) Control and (5) Despair. The themes were separated into two distinct phases: (1) when participants were in the moment of the attack of pain and (2) in-between attacks. The former phase came with visceral, emotional, crisis-like, primal experiences, whereas between attacks, psychological experiences contained more cognitive functioning, such as planning and rumination. Theme one (Darkness) related to the experience of the attack of pain and comprised of two subthemes: (1) the horror-like quality of the painful attack and (2) participants negative thoughts throughout the attack, including suicidal ideation and self-blaming thoughts. Theme two (Battling) was also comprised of two subthemes: (1) fighting against the pain in the moment of the attack, for example, through pacing and hitting one’s head and (2) fighting for visibility and acknowledgement for the condition outside of the attack, both from healthcare professionals and the public. Theme three (Shifting) related to the dramatic “shift” between being in and out of an acute painful attack and between being in and out of a bout period for episodic sufferers. Theme four and five related to experiences between attacks. Theme four (Control) was separated into the subthemes “Knowledge” and “Planning” and referred to participants gaining a sense of control over their condition through receiving a diagnosis, understanding the science behind the pain and planning their daily life to account for the attacks. Finally, theme five (Despair) related to the sense of hopelessness, depression and exhaustion which was evoked by participants’ accounts of living with CH, whereas theme one related to acute, dark cognitions and theme five related to a more long-term psychological distress, which came from ruminating about one’s condition and the impact on life. Theme five was particularly present for CCH individuals. See the thematic analysis map in Figure 1 for themes and subthemes.

Each of the themes is detailed below alongside quotes. Removal of text is denoted by [. . .], and (text) explains context of quotes. Next to each quote is the participant's number, gender and CH subtype.

3.3.1. *Theme One: Darkness: In the Moment of the Attack*

3.3.1.1. Evil Phenomenon. The theme "Darkness" relates to an almost other-worldly, evil, horror quality which the researchers felt was evoked from many participants' accounts of when they were in a CH attack. Participants often struggled to articulate their experience, finding it difficult to put into words something so different from their usual, pain-free state.

> You can't even describe the pain when you're not having it [. . .] I think of it now and again as the monster. I also think of it as every foul word you can think [. . .] when it's there, I want it to go away and it's horrible and evil. (P7, M, Chronic).

Participants spoke about their CH attacks as being a separate entity with ill intentions against them. It could be that CH sufferers externalised their pain in this way to separate the "evil" entity from themselves, so reducing self-blame and maintaining a coherent sense of self. It is interesting to consider whether the dark interpretation of CH relates to pain catastrophising, which was raised in 64% of study participants' results.

> It's very dark as well. You just think it's it's like, it's er I don't wanna, this sounds very odd, it's like, it's like it's out to get ya. Like a really, like it's coming for ya [. . .] You'd go through your, you know that expression, "the dark night of the soul?" (P12, M, Episodic).

The hesitancy in the way P12 spoke perhaps indicates awkwardness with sharing their experience, or even fear, due to the other-worldly, strange quality.

Several participants also spoke about their experience in spiritual terms, referring to God and punishment.

> This has gone into the family vocabulary now, so now a Cluster Headache is an attack of being smited by God. (P13, F, Episodic).

CH attacks often occur at night, which may have contributed to the dark and other-worldly associations.

3.3.1.2. Dark Cognitions. Within the theme of "Darkness" was also the subtheme "Dark Cognitions" within the moment of the attack. Individuals reported negative, blaming and thoughts about themselves.

> My mind goes to some quite dark places. So like during the cluster headaches you, you end up thinking like all kinds of ridiculous things. Like you know, "is this my fault? Is this happening? Is this being sent by God to make me a more understanding (healthcare professional)"? (P4, F, Episodic)

Some participants spoke about suicidal thoughts throughout the attack to stop the pain.

> If there was a pill that would kill me, I would take it [. . .] because I can't bear it. (P10, F, Chronic).

Given CH is nick-named "the suicide headache," these experiences are perhaps unsurprising. For all individuals who spoke about suicidal ideation, this was isolated to the moment of the attack, related to stopping the pain, and they had never acted on such thoughts. For example, P10 clearly stated "I do not wish to die, I have a lovely life." This process of cognitions shifting when in and out of attacks was a common experience, with individuals sharing that it was hard to think logically when in extreme pain.

> In that intensity of pain [. . .] It's it's a different state of being in terms of how you think. You literally have such a thin layer of consciousness [. . .] it's almost like you're drowning. (P5, M, Episodic).

Due to the passive nature of suicidal ideation, no follow-up with participants' GPs was deemed necessary.

3.3.2. *Theme Two: Battling*

3.3.2.1. Battling With the Pain: In the Moment of the Attack. This subtheme relates to how individuals cope with the "Darkness" during attacks. Some participants described fighting against the pain throughout an attack, through pacing, throwing objects and hitting their head. This is an experience previously reported on with such behaviours being used as a diagnostic marker to differentiate CH from other primary headache disorders.

> I like turn into a different person. It is quite frightening because I can't talk. You know, I I get very very frustrated, extremely agitated [. . .] I just wanna hit my head against the wall sometimes. (P10, F, Chronic).
>
> If you try and read while you're having it (an attack), you end up throwing the book across the room [. . .] I've punched erm a bedpost. (P4, F, Episodic).

Whilst battling with the pain was a common experience, several interviewees reported changing their psychological response over time, moving from fighting the pain to "grinning and bearing it" (P11, M, Episodic and P6, M, Episodic). Several mentioned they have mantras they repeat to themselves. P6, who had lived with CH for several decades, said the following:

> You don't get complacent to it all, but you kind of looking and think I've had a million of these now I can deal with these. (P6, M, Episodic).

These changes from battling against the pain towards trying to be with the pain may be indicative of sufferers coming to a place of acceptance for their condition.

Several participants took this further, speaking about trying to relax throughout an attack and breathing deeply. They reported realising, over years, that becoming agitated was likely "feeding" (P12, M, Episodic) the pain. Several theorised that increased heart rate and becoming tense could not be helping.

> I try to stay calm [. . .] probably a decade or so ago [. . .] I just kind of concluded that like, you know, kind pacing and getting agitated and stuff, you know, kind of surely that can't be helping. And I used to, I used to like hit back and I hit my head. (P2, M, Episodic).

P5 expanded further on this, describing how they tried to separate from the pain and in so doing tried to ride the attack out:

> In an attack I've I've worked myself into position where I can distinguish the two. I can feel the pain in my head, right? But [. . .] I am not the pain [. . .] For the longest time, I was the pain and I would be on the floor, I would be banging my head against the wall trying to relieve it [. . .] But in my latest attack [. . .] I could try and dissociate from the physical pain. (P5, M, Episodic).

P13 also spoke about a different approach to battling the pain. They used humour when referring to the pain to make it easier to cope with. This humour involved referring to the condition in dramatic terms.

> Making something of a joke of it and some of my friends will use it. You are not going to let it beat you. It's like erm people making fun of Hitler during the war, takes the horror out of it out. (P13, F, Episodic).

3.3.2.2. Battling for Recognition: In-Between Attacks. Outside of the moment of pain, participants described a battle related to seeking recognition and support for the condition.

> You have to do a lot of battling at a time when you're not in the mood to be battling. (P3, M, Episodic).

Many said the battle for support was due to lack of awareness and understanding of the condition; particularly from GPs. Furthermore, participants felt that the name "Cluster Headache" undermined and diminished the severity of the condition, with the public likening CH to other headaches or migraine. This experience was often accompanied by emotions of embarrassment and frustration.

> I hate the word cluster headache, I just hate it. I hate the phrase, I hate saying it because it undermines what it is [. . .] It makes you feel stupid because (chuckles) you know people just think "oh she's always off with a headache". (P10, F, Chronic).

Several participants felt that the lack of physical symptoms and invisibility of the acute pain during a headache attack meant the public could not understand the level of distress.

> It's the visual representation, if you know, if we had blood pouring out of our eyeballs, people would notice. (P2, M, Episodic).

Again, this quote uses dark, horror-like language to describe the experience, linking it to the "Darkness" theme. Such evocative language to describe the CH experience could be used as a vehicle to share the invisible experience of pain, so others can try to understand and empathise.

The researchers reflected that the sense of battling for recognition was also evident by the project being proposed by an individual with CCH and through the huge response to the study advertisement. There was a sense of almost desperation to have ones' experiences heard.

Interestingly, P4 had a different experience, feeling their experience was always understood and validated. They were a medical professional and said that because CH is known as a very painful condition in the medical world, they had never been doubted. This participant also expressed that the fact CH is more common in males means that the severity of the pain is believed.

> I'm quite lucky because uh, it's a condition that mainly affects men [. . .] So all the medical textbooks say [. . .]"it's the most painful condition known to man" [. . .] Whereas medical conditions that mainly affect female the medical textbooks traditionally say things like "this is probably all psychological, and there's no point in trying to fix it" [. . .] So everybody's very sympathetic. (P4, F, Episodic).

However, P4 went on to share that there is a lack of attention from a mental health lens, something echoed by other participants. P4 explained that the shared understanding that CH is "the suicide headache" means that when people voice this, it does not evoke the appropriate response of support.

> If you say to a (healthcare professional) "my COPD is so bad I wish I was dead" [. . .] it's a prompt for everybody to be like "oh my gosh, do we need to do a mental health services" [. . .] erm but if you say "my cluster headaches are so bad I wish I was dead" everyone's like "oh yeah classic textbook presentation" and it doesn't, and I feel like it just stays as like a diagnosis thing. (P4, F, Episodic).

3.3.3. Theme Three: Shifting. This theme relates to the jarring experience of shifting from being in and out of pain. Participants described how, with no warning, they could go from being completely pain-free to being in incredible pain. Individuals reported that this made planning difficult, resulting in anxiety about upcoming events. Furthermore, several participants commented that the sudden, dramatic onset meant that their pain was often not believed.

> 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 erm people seem to think you're making it up. (P10, F, Chronic).

The Shifting theme also relates to episodic sufferers' experience of being in and out of a bout season. Participants described almost a change in who they were as a person and their identity, a healthy "normal" person, to someone incapacitated by illness.

> Most of the the year, it's like that plain, clear skies. Beautiful, right? [. . .]. But then during my cluster season, it's like you hear thunder, [. . .] you see the clouds forming and and then the storm hits you [. . .] and then that will be it for six weeks. (P5, M, Episodic).

Episodic sufferers often spoke about the feeling of freeness once out of the bout, not remembering the pain and living their life with no impingements.

> When you realize that you're out of them, it's like, you know, happy times. Let's let's go out, let's celebrate [. . .] I'm a happy go lucky chap out of my bouts erm, I'm I'm fully pain free. (P6, M, Episodic).

P2 expanded further, expressing that out of bout season, they were in denial of their pain, making it easier to focus on engaging with life.

> Between the bouts I'm definitely in denial about them. So actually I would kind of forget about it if that makes sense and which is which is kind of a good thing. So I've never, I've never not planned something in case I get them. (P2, M, Episodic).

However, P3 did not share these experiences, stating that between bouts they were focused on the next one.

> It'd be nice to feel like the weights lifted off your shoulders, but it doesn't because you're more you're already thinking "when's the next bout"? [. . .] it doesn't sort of leave you. (P3, M, Episodic).

Furthermore, several participants spoke about the catching up they had to do between bouts/attacks. For example, P4 was a month post their last bout:

> I'm kind of trying to pick up the pieces a little bit about my life. (P4, F, Episodic).

Of course, CCH sufferers did not have the experience of being out of bout season. Therefore, the condition was always there, which came with emotions of tiredness and a sense of despair, which relates to theme five.

> You can just feel like it's just one long horrible road of pain and you know, feeling ill all the time. (P10, F, Chronic).

Interestingly, P7 took a different stance to the chronicity of their headaches, stating they felt that episodic sufferers had a worse experience due to increased uncertainty and unpredictability in pain patterns.

> It's even worse for them (episodic sufferers), I think, because erm because their life gets completely interrupted. Where mine is mine doesn't start because because this is part of it. Tonight, I'm almost certainly gonna wake up a few times (in pain). (P7, M, Chronic).

3.3.4. *Theme Four: Control: In-Between Attacks*

3.3.4.1. Knowledge. All participants spoke about the defining moment they received their CH diagnosis and understood what was happening to them. This diagnosis often took years due to perceived failings from the NHS. It was common for individuals to believe they were suffering from a life-threatening illness prior to diagnosis. This knowledge seemed to help them feel less concerned by the condition and allowed them to start taking control of helping themselves.

> When they first started, I was very very concerned and I thought I was probably having a brain tumour [. . .] Once I'd sort of started seeing more specialists and things, they really were reassuring. Erm, and over over the years I've gotten to accept it is it is what it is. (P11, M, Episodic).

All participants were incredibly knowledgeable about CH. Participants reflected that this knowledge was obtained through having lived with the condition for so long and from self-learning, rather than the information being provided. Individuals seemed to always be trying to learn more about the condition and how to manage it.

> I know it so well (because it's happened) thousands of thousands of thousands of times. (P8, F, Chronic).
>
> Invariably erm my Google search history changes quite drastically when I'm in a bout, cause you constantly trying to search for answers. (P3, M, Episodic).

Having a physiological understanding about the condition seemingly helped participants detach/separate from the dark, evil quality of the condition identified by theme one "Darkness" and made it easier to manage the pain.

> It's probably something to do with some chemical some some hormones being released which regulate the body clock [. . .] so I'm quite happy having this chemical enemy if you like [. . .] rather than some entity which is making me feel bad because it doesn't like me or he wants to punish me. (P7, M, Chronic).

Furthermore, this medical understanding helped participants feel more in control of their experience through lifestyle changes.

> It (the physiological understanding) takes away that sort of doom and gloom and it it if something's happening in my body, if something's happening in my brain and that it's my pituitary gland, my hypothalamus somethings going on. You know, I think I've kind of like with the amount of supplements I'm taking and and the why I'm healthily eating, cut out sugar cut out carbs and stuff, and I'm I'm getting a lot of fat. I'm feeding my head basically. (P12, M, Episodic).

3.3.4.2. Planning. As well as becoming knowledgeable about the condition, participants spoke extensively about the medication and lifestyle changes they had tried over time. They referred to routines they had developed which helped them plan for future attacks and feel calmer and more in control.

> I've got my own little kind of routine that I get into when it's happening [. . .] That's that's worked for me because I don't panic. (P12, M, Episodic).

All participants verbalised a complete reliance on routines to manage the pain. Throughout the interviews, participants would often keep coming back to speak about these pain management strategies, particularly medication, even if the interviewer tried to move the conversation on. This likely highlighted the clear salience of these strategies for people. This reliance on pain management routines may have related to low self-efficacy; indeed, 72% of the participants scored below the level indicative of low self-efficacy:

> The thoughts of being out somewhere and starting with an attack and not having any access to (medication) I can't. That that I I can't, it's a bit like being caught out in the middle of town with no clothes on. (P1, M, Episodic).

It was also common for individuals to plan upcoming events around their headaches.

> We didn't book a wedding in (a certain month) because I had got cluster headaches in (this month). (P4, F, Episodic).

However, others took an approach of trying to not plan around the CH and to not let the condition consume their life. This was particularly true for individuals who had lived with the condition for many years. Furthermore, CCH sufferers, who did not have remission periods, spoke about having no choice but to continue with life events.

> If I let it (cluster headache) be front and centre with everything [. . .] I would literally never go anywhere or do anything, and I can't do that and I wouldn't do that to my family and friends because it's not fair on them [. . .] It is always in the back of my mind, I worry, you know, Christmas, birthdays. (P10, F, Chronic).

> What's the choice? You lie down and die, or you go to bed permanently, or you just carry on and have as much of a life as you can. (P8, F, Chronic).

3.3.5. Theme Five: Despair. The final theme identified was despair, meaning hopelessness, depression, exhaustion and negative thoughts. This related to feeling distressed that life was interrupted and being physically drained by repeated intense pain. This theme was particularly present for CCH sufferers, which perhaps is understandable considering they do not have the respite from pain that episodic sufferers experience.

> Why wouldn't you be depressed? Your life is impacted, you're in pain, you can't do the things you used to do, you're continually brought up against your limit. (P8, F, Chronic).
>
> It does make you feel extremely drained as well. Like afterwards, I'm just like a wreck because I just feel like someone has zapped all of the energy out of me. (P10, F, Chronic).
>
> It's depressing, it really gets you down. [. . .] there's no, no end to it really. [. . .] I know of people who have committed suicide because of it [. . .] it's not my way out [. . ..] I can fully understand how people get to desperation point. [. . .] you can't see an end, you know, to the pain. (P9, M, Chronic).

Some participants spoke about the negative thoughts they had about themselves throughout bout season.

> P12 stated that physical pain caused "deep emotional pain", dwelling on the past and thinking "terrible things about yourself". (P12, M, Episodic).

Several participants spoke about their thoughts becoming less negative over time. P5, who had had CH for many years, said

> 10 years ago, uh, there's a lot of fear [. . .] Because I didn't know what it was [. . .] I thought like a tumour, I thought cancer [. . .] There was a lot of woe is me [. . .] the world is horrible to me, it's not fair. (P5, M, Episodic).
>
> P5 said that now having a "label" and knowing "I'm not about to die, even if it feels like that" meant that now "whatever negative thoughts I feel are all about relieving that pain" rather than negative thinking. The importance of a diagnosis is something which is echoed in many chronic pain conditions, and indeed health conditions more broadly. Moreover, this relates to the theme of "Control."

Similarly, P4 stated that they now tried to challenge irrational thoughts. However, they spoke about the buildup of fatigue over the course of the bout making this balanced thinking progressively more challenging. This would be an important consideration when thinking about psychological interventions for CH sufferers. It may be that cognitive treatment throughout a bout may be difficult to engage with, and instead psychological interventions outside of bout season would be preferential. Of course, this would not be possible for CCH individuals.

> I try and do that (challenge thoughts) but obviously I get worse erm, the worse the pain is, and the less sleep I've had. (P4, F, Episodic)

Despite individuals feeling hopeless, there was a general sense of individuals not allowing themselves to be beaten by their pain. Furthermore, there was a clear wish to share this hope with other sufferers. The interviewer reflected that they felt these emotions throughout the interview, with there being moments they felt despairing as the participants spoke of their condition; however, the interviewer always felt hopeful by the end of the interview. They also felt a strong desire to advocate for CH sufferers, which links to the "Battling" theme.

> It's a nightmare this condition [. . .] it's really, really awful. It's not well understood, the treatments are limited [. . .] but don't give up [. . .] would be my message. To anyone who's starting on this nightmare [. . .] Don't give up. You know you will find some way to manage it. (P8, F, Chronic).

4. Discussion

This qualitative study aimed to explore the psychological experience of CH. RTA identified themes and (subthemes): Darkness (evil phenomenon and dark cognitions), Battling (with the pain and for recognition), Shifting, Control (knowledge and planning) and Despair. The themes existed within specific phases are as follows: (1) in the moment of the pain attack and (2) between attacks. All participants reported the jarring shift between being in pain and pain-free. For ECH sufferers, this pain-free period could last for a substantial time, and many reflected feeling like a "normal" person in this period. As CCH sufferers did not have such periods, the psychological experience felt distinct between the subtypes. CCH sufferers appeared to experience more despair and depression, whereas ECH sufferers often felt happy outside of bout season, but did also experience more uncertainty as their life was suddenly disrupted by the condition.

4.1. Main Findings in the Context of Previous Literature

4.1.1. Darkness Theme. To the authors' knowledge, this is the first study to identify the dark quality of the experience of CH. Previous research has noted that individuals describe the intensity of CH pain using vivid language [8, 20] but has not commented on the other-worldly, evil, almost spiritual atmosphere, evoked by participants' accounts of a cluster attack. The research team reflected that this theme felt very lonely and was the most powerful theme due to the metaphorical language used, such as referring to the attack as "the monster." Using detailed stories and metaphors to describe pain is seen more widely within the chronic pain field. It has been suggested as a strategy to share the invisible pain experience with others and evoke empathy [52–54].

Within the theme of "Darkness" was also "Dark Cognitions," including suicidal ideation. Several participants referred to suicidal thoughts throughout the attack to stop the pain. This finding is perhaps unsurprising given CH is known as "the suicide headache" [11], and research has reported higher rates of suicidality amongst CH individuals compared to nonheadache controls [55–58]. Current study participants were clear that outside of attacks they did not have suicidal thoughts. This experience is comparable to findings by Ji and Lee [59] who explored 175 CH patients and reported suicidality throughout an attack which reduced between attacks. It is interesting to consider whether the reputation of CH being associated with suicidality results in healthcare professionals viewing this as a diagnostic marker rather than catalysing mental health support, an idea speculated by Participant 4.

4.1.2. Battling Theme. The "Battling with the Pain" theme related to participants becoming behaviourally agitated throughout attacks. This is an experience previously reported on, with such behaviour often being used to differentiate CH from other primary headaches [2]. The agitated behaviour arguably relates to the fear–anxiety–avoidance model of chronic pain [60]. This model proposes that when one perceives pain, their appraisal of this pain influences their behaviour and physiological response. If one catastrophises their pain, such as thinking the condition is a monster/evil (Darkness theme), this can result in physiological arousal and escape/defensive behaviours. Arousal results in increased heart rate and muscle tension, which counterintuitively can exacerbate pain [61–63]. Some interviewees spoke about, over the years, learning that battling was not helping and so tried to relax instead. Interestingly, all the participants who tried to relax had scores on the pain catastrophising questionnaire below the threshold, whereas most participants were above the threshold. It may be that less catastrophic interpretations of their pain allowed them to respond in a way which was more adaptive, i.e., not battling the pain.

The theme "Battling" also included "Battling for Recognition" which involved feeling misunderstood by those around them and let down by the NHS. These experiences parallel with the two previous qualitative studies which explored CH experiences [20, 21] and more broadly with experiences of those with chronic pain conditions [64, 65]. Participants in both the current study and the Andre and Cavers [21] study voiced disliking the term "Cluster Headache" as it undermined the severity of the condition.

4.1.3. Shifting. Theme three is related to "Shifting" between being in and out of pain. Sufferers depicted having almost two lives and identities. This experience of shifting is seen in many chronic diseases [66]. When one suffers a chronic illness, the presence of illness can be inconsistent with one's previous healthy identity so causing identity-discrepancy and psychological distress [67]. Illness identity is how much one's illness is incorporated into their overall identity [68], and it is suggested that coming to accept illness into one's overall identity is more adaptive as it encourages better self-management [69–71]. Individuals in the current study, who had been living with CH for many years, spoke about changing the way they responded to their condition, going from a position of battling against the pain, being hypervigilant to triggers and avoiding social events to trying to relax with the pain and continue engaging with life. This could be likened to coming to accept one's illness.

4.1.4. Control. The theme of "Control" through knowledge and planning reported in the present study draws parallels with the previous qualitative UK CH study [21]. Andre and Cavers [21] highlighted the huge moment participants received a diagnosis, and how this catalysed a process of self-learning about CH. Participants in both the present study and the study by Andre and Cavers [21] seemed to develop well-established routines, often involving medication, to manage the pain. Both studies' participants appeared dependent upon these routines, perhaps indicating low belief regarding their ability to cope with pain. Low self-efficacy may be an important aspect in the theme of "Control." Indeed, 72% of the current sample scored below the level indicative of low self-efficacy.

In both the current study and the previous UK study [21], some participants spoke about planning their lives around CH. This involved not planning important events in bout season and avoiding triggers. However, it was common that such hypervigilance restricted individuals' lives and participants voiced the conflict of trying to plan for CH whilst not allowing it to dominate. This aligns with the fear–anxiety–avoidance model [60] which proposed that fear of pain and resulting reduction in activity to try and reduce pain exacerbates pain through deconditioning and reduced engagement with life [72]. Successful headache treatment involves gradually reintroducing activities to increase desensitisation and quality of life [73]. Perhaps CH sufferers have learnt over time to do this independently.

4.1.5. Despair. Whilst the "Darkness" theme depicts negative cognitions throughout the acute attack, the Despair theme instead relates to the longer-term sadness and exhaustion that comes from living with the condition and contemplating the impact on one's life. The theme "Despair" echoes previous literature. Two previous qualitative studies exploring CH detailed experiences of depression and life stopping throughout bout seasons [20, 21] and research reports higher rates of depression in CH adults compared to nonheadache controls [55, 56, 74]. This theme was particularly prominent for chronic CH sufferers, which is perhaps unsurprising given they do not experience significant remission from the pain. This idea that the despair is more prominent for chronic sufferers is supported by two studies which reported higher rates of depression amongst CCH individuals than ECH individuals [57, 75].

4.2. Strengths and Limitations. A PPI representative suggested that this research topic was involved throughout the research process. This design is in line with NHS planning documents, which highlight that involving PPI representatives in research empowers patients and promotes improved care [76–78]. The use of OUCH for recruitment meant that the sample may have been biased towards digitally literature individuals, so limiting transferability of the findings. However, the demographics of the sample, in terms of gender and type of CH, reflected the CH epidemiological profile [4]. Thematic analysis is invariably a subjective and bias process [44]. The research team accounted for this through the primary researcher keeping a reflective journal and then reflecting with others in the research team, mostly importantly the PPI representative, to embed their voices/interpretations. The findings were concordant with pre-existing literature conducted in both similar and different contexts (UK and Spain; [20, 21]) perhaps suggesting the subjective process did not bias study results significantly. Thematic analysis also comes with a challenge of balancing breadth of experience, with depth [79]. Authors identified that the "Darkness" theme felt powerful and could have been explored in further depth. However, as this was the first research of its kind, it felt appropriate to explore a range of experiences. Future research could employ Interpretative Phenomenological Analysis which examines individual experience in detail and is useful for emotionally laden, elusive, phenomenon (Smith & Osborn, 205).

4.3. Clinical Implications and Future Directions. This research emphasised the need for increased visibility of CH, both within the healthcare world to improve diagnosis and treatment and within the public generally to increase empathy and understanding. Authors recommend research to explore how greater awareness can be achieved, be that through changing the name "Cluster Headache" or through public health campaigns. Furthermore, currently individuals seem to become knowledgeable about their condition through independent discovery. Having a consultation postdiagnosis where one is informed about the condition is recommended to support individuals to feel more in control.

This study identified the complex psychological experience related to CH. Psychological experiences appeared different in the acute attack, between attacks and between bouts for episodic sufferers. Throughout an attack, participants reported a visceral, almost nonhuman experience and how they often responded through "battling" against the pain. Between attacks, experiences were more cognitive and included planning for the next attack, seeking recognition for their condition, rumination on the ramifications of living with the condition and exhaustion from ongoing pain. Accounts suggested that the psychological experience was distinct for ECH and CCH individuals. As CCH individuals did not experience respite from the pain, this often came with more depression and despair, but also a sense of certainty of the pain. In contrast, ECH sufferers often reported feeling free and happy outside of bout season but also a sense of dread and uncertainty of when the next bout would occur. These findings are important when considering treatment options in the future. For example, it has been speculated that psychological support could be offered in headache free periods, when one is not exhausted and drained, in preparation for attacks [19]. Importantly, CCH sufferers do not have remission periods, so timing would need to be individualised. In fact, when researching CH going forwards, authors recommend considering viewing the subtypes as distinct and so exploring them separately.

4.4. Speculative Discussion. From the interview data, authors identified that 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. Participants had not received psychological input, and so these were learnings they developed independently. This could suggest that fighting against pain, avoidance, potent negative catastrophic cognitions and lack of control may maintain distress in the CH experience. Whilst this must be directly explored with CH individuals, this idea is supported by research on Migraine and TTH individuals, which found that low self-efficacy, pain catastrophising, activity avoidance and anxiety have been related to longer and worse head pain [80–82]. Authors call for exploration of these factors on CH individuals to understand the nature of these factors and the extent to which specific factors are associated with maintaining suffering.

Once a clear psychological formulation of CH is defined, there is potential to develop psychological treatments and adapt NICE guidelines to include such treatments. These treatments could involve adapting existing evidence-based approaches, as factors speculated on by this research are easily recognisable from existing evidence-based psychological models. Indeed, the idea of stopping battling against pain has similarities to psychological flexibility in ACT [83] and remaining calm through attacks has similarities to distress tolerance grounding techniques in dialectical behavioural therapy (DBT; [84]). Further, engaging with life, not avoiding situations and changing one's thoughts have parallels with behavioural activation, exposure therapy and cognitive restructuring in CBT [85, 86].

5. Conclusion

This PPI-directed study demonstrated the huge burden placed on those living with the primary headache condition, cluster headache. Authors call for greater awareness of the condition to ensure delayed diagnosis and lack of understanding from the public does not exacerbate the burden. The psychological experience seemed distinct between ECH and CCH individuals, which is perhaps unsurprising given the former comes with significant remission periods from the pain, whereas the latter does not have such respite. As complex psychological processes have been identified here, authors call for future research to explore how psychological approaches could improve the lives of those with CH, perhaps exploring the two subtypes separately. Research should explore these ideas using PPI-directed research to ensure authentic, sincere, work is conducted which meets the needs of the CH community.

Data Availability Statement

Full transcriptions are not publicly available to protect participant confidentiality. An example of the coding process for one theme is available upon request to the authors.

Conflicts of Interest

The authors declare no conflicts of interest.

Author Contributions

Helena Whitley: conceptualisation; data curation; formal analysis; investigation; methodology; project administration; software; visualisation; writing–original draft preparation; and writing–review and editing. Wayne Nolan: conceptualisation; methodology; and validation. Elisabeth Norton: conceptualisation; supervision; writing–review and editing; and validation. Fergus Gracey: conceptualisation; supervision; writing–review and editing; and validation.

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General Statement

'What is already known on this subject?'

- Cluster headache has been associated with increased psychopathology, including depression and suicidality.
- National Institute for Health and Care Excellence (NICE) guidelines for treatment in the United Kingdom (UK) are all related to medical interventions and are limited in effectiveness.
- Qualitative research has highlighted that cluster headache individuals feel misunderstood and experience significant burden.

'What does this study add?'

- This was, to the authors' knowledge, the first study to explore psychological processes occurring for individuals with cluster headache (cognitions, behaviours and affect). This study identified the complex psychological experience related to CH, which can be separated distinctly into the acute attack and between attacks.
- This study identified psychological processes which may be maintaining distress for cluster headache individuals: fighting against pain, avoidance, potent negative catastrophic cognitions, lack of control and lack of understanding from others.

- This study identified how the experience is distinct for individuals based on the subtype of cluster headache they have, chronic or episodic cluster headache.

Supporting Information

Additional supporting information can be found online in the Supporting Information section.
Supporting Information 1. S1: Consolidated Criteria for Reporting Qualitative Studies COREQ-32.

Supporting Information 2. S2: GRIPP 2 Short Form for PPI.

Supporting Information 3. S3: Interview Schedule.

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