



Study Findings: A Qualitative Exploration of the Experiences of People Living with Cluster Headache.

This document provides a summary of the key findings from the study 'A Qualitative Exploration of the Experiences of People Living with Cluster Headache'. As the study was qualitative, the main focus of the interviews was on the individual and their personal experience of cluster headache. Each interview was analysed to identify similarities, or 'themes', that were common across all of the interviews. Overall, three key themes were identified: 1) Not "just a headache": Living with a misunderstood condition 2) Adapting to cluster headache 3) Struggling for control.

A general overview of the findings

In general, participant's descriptions of living with cluster headache varied in several areas, including: the time of day or year their attacks start, how long they lasted for, the intensity of pain, and their individual triggers. Despite this variety, all participants described a similar experience of extreme and aggressive pain:

I have had quite a lot of injuries over in my life, I used to play a lot of rugby so I sort of dislocated my shoulder and ruptured ligaments and broken bones and all that sort of stuff. I've never had anything that was even remotely on the same scale of pain as a cluster attack, not even, not even vaguely close. – P10, M, 25-39, Episodic

Most participants also talked about the negative impact it had on their mental health. They described worrying when the bout will start, feeling lonely, low or depressed, mainly due to the fact that they withdraw from social situations during their bouts.

1) "Not just a headache": Living with a misunderstood condition

A key theme that featured across all ten interviews was of participants feeling misunderstood by others as a result of a lack of awareness of their disorder. Although each participants' experience was unique, all spoke of a gap between the intense pain that they experience, and how it is seen by others. They believed that people viewed cluster headache as "just a headache", or a minor issue, and felt the extent of their suffering was not seen as legitimate:

I don't think that people understand, I think that's just across the board thing. Like illnesses that people can't see, they just don't understand, do they? They are like "well you look fine" [...] Yeah, I think that's, that's quite hard for other people to understand. Um, because I know my husband's family, they think it's just a headache and I just make a bit of a, being a bit of a pansy. – P9, F, 25-39, Episodic

In particular, several participants voiced frustration with the way cluster headache is constantly compared with migraine. They reported believing migraine is the less painful disorder, and such comparisons therefore belittled their experience:

Even close relatives in my family, they still don't have any concept of how bad it is to live with, you know, because they don't see you when you're having attacks and what it's like in your home [laughs]. [...] People think "oh, it's just a headache", you know, "it's just a migraine", you know, and they are worse than migraines, they really are. – P1, M, 40-60, Episodic

Most participants described a lack of awareness and understanding of cluster headache as particularly being a problem amongst GPs. The majority of participants described the negative impact this lack of understanding among the medical profession had in terms of their care. Interactions with GPs were described as "battles" (P7, F, 40-60, Chronic), with seven participants



facing lengthy delays in diagnosis and referrals to specialists. Their descriptions of the process of diagnosis revealed feeling like they were being dismissed, typically resulting in them being misdiagnosed, and left without access to treatments:

I first started having attacks when I was sixteen but I wasn't diagnosed with cluster headache until I was thirty-one. So, I went through a period of fifteen years, in my teens they basically misdiagnosed me with a whole load of stuff. They put me on beta blockers, warfarin, Prozac, loads of stuff that didn't work and I became quite depressed and disillusioned with the medical establishment and didn't go back to a doctor about it for a long time. – P10, M, 25-39, Episodic

2) Adapting to cluster headache

Another key theme that was identified was around participants attempting to make sense of their lives following cluster headache onset. For certain participants, cluster headache had an overwhelming impact on their lives, where they voiced a sense of loneliness, loss and change in their former lives.

For three participants, primarily chronic sufferers, working on a regular basis was essentially impossible. This was particularly severe for participant 7, a recently diagnosed chronic sufferer, who described being unable to leave the house due to the number of attacks she faced. The impact upon her work was particularly described as impacting upon her identity and self-esteem:

I've been somebody who you go to work, you do your stuff, I'm sort of a busy person and from sort of really the middle of August, certainly the September as things got worse and worse, I haven't driven, I haven't been at work so we're about £40,000 poorer off. There's all this uncertainty and things. [...] And it's really hard because you know, my work was more than just work. It was something that I was really passionate about. – P7, F, 40-60, Chronic

Six participants also described the way in which cluster headache severely impacted their hobbies, social life, and family life. During bouts, these participants described withdrawing, shutting themselves off, and limiting their activities in an attempt to control the pain. This was seen as causing an identity crisis, and was described as adding to their sense of loneliness:

I love going to the gym, it's not a chore for me, but I just couldn't. I just didn't have the motivation to do it because I felt so exhausted and ill and horrible. [...] So, it really impacted like on that and I think the gym for me was like a social thing as well as – and obviously like the martial arts I used to do as well was a social thing as well as something I used to do to keep fit. So, I just stopped that. – P2, F, 40-60, Episodic

In contrast, several of the participants described ways in which they attempted to adjust to their life with cluster headache. These participants tended to be episodic sufferers, who had fewer attacks than some of the other participants. They described having a more positive outlook and being more in control of the disorder. For example, while regular work was impossible for the three of the aforementioned participants, others described having supportive employers and flexibility at work. This enabled them to avoid their triggers and pace themselves, creating a sense of normalcy in their life:

I had a really slow phased return to work and I'm really fortunate in that with my job in that I can work from home so now I work from home so I can not have any smells, I can work in the dark [...] So, if I can feel, I'm really aware of feeling or sort of the feelings before you're going to start getting bad, so I tend to just sort of minimise the things I'm doing. – P2, F, 40-60, Episodic



For the majority of participants, however, accepting the situation was often far from their minds. Instead, the hopelessness and pain were described as negatively impacting their mental health:

It really gets you depressed really, um, obviously when you've got the attacks, uh, I do go through real serious depression and it even effects my wife, she gets depressed of, you know, of being in the house with me and the lack of things that we can do. [...] Uh, and there have been times where I've been really suffering and none of the treatments are working, you know, that you do get suicidal thoughts, you know, it's, it's that bad. – P1, M, 40-60, Episodic

Several participants, with the exception of those who had been free of attacks for years, described the way in which they not only suffer when they are in a bout, but their experience of cluster headache is also associated with anxiety and dread of attacks starting. These participants describe how they are never truly free of these negative emotions, and struggle to adjust to a life with cluster headache:

*And then when they came back, I just thought "oh sh*t, you know, they're back again, when's the next one gonna be?". So yeah, that's, that's really the way that they affect me on a non-episodic basis. That's the chronic side of what I suffer. There's that dread and fear, and then of course when the episode starts, it's, I forget about all that, I'm just worried about getting through. – P3, M, 40-60, Episodic*

3) Struggling for control

Another theme that was identified across all ten interviews was of participants attempting to control the impact of cluster headaches, which can often never completely be achieved and comes with a cost. Participants described learning about their bodies over time, discovering and avoiding known triggers, and experimenting with a variety of treatments in an attempt to control cluster headache and its impact. As part of this, participants frequently had to weigh the risks and benefits of certain activities. They also discussed the impact that trying to control cluster headache had on their sense of self, and how this often adds to their sense of loneliness.

Over time, participants developed their own individual coping strategies to help them get through an attack, such as rocking or pacing around the room. Despite having different coping strategies, most participants described needing to remove themselves, and to be alone during attacks. They also voiced the fact that, beyond OUCH, support for sufferers to help them cope during bouts is lacking. Although they needed to be alone during the attacks, they highlighted that the timing of support is crucial, wanting somebody to speak to in the periods when they aren't having attacks:

You almost need, I don't know, like a – someone at the end of the phone to just go "oh I've had a rubbish day" and then almost or maybe something online of sort of a self-care pack almost. - P2, F, 40-60, Episodic

The participants' experiences of trying to control the impact of cluster headache was dominated by an ongoing process of weighing the benefits and risks of certain actions. For many participants, watching out for triggers and being disciplined in avoiding them where possible was one way of asserting control over their cluster headaches:

Yeah, I mean I've read alcohol may trigger it. I don't drink that much and that often. I did have, I went out on Friday and I had two glasses of wine with a meal with my boyfriend and I had about three hours later I had my normal 9 o'clock headache but it was really, really bad and I was like "right, that's it. I'm not having any alcohol" [laughs] [...] So, yeah, I'm like until these headaches stop, I'm not drinking again. – P5, F, 40-60, Episodic

When participants went to great lengths to avoid their triggers, they described the fact that it can also lead to their lives being controlled by the disorder. Many participants described avoiding social



situations during bouts for fear of triggering an attack, which added to their feelings of loneliness. Several participants also described the all-encompassing nature of cluster headache, where they lived in fear of accidentally triggering an attack and therefore took measures to avoid all potential triggers:

Yeah so, I do definitely live in fear. [...] I've basically stopped drinking because of it and you know, just anything that I can do to just stop. Because they also said that maybe strong smells can do it as well, so I now don't have any strong smells in the house. No candles, no bleach, no anything cleaning related. [...] Yeah, I literally changed my whole life just to try and not to have them, basically. – P9, F, 25-39, Episodic

Being prepared with medication to stop the pain also emerged as a way of trying to control the pain of the attacks. Several participants described their dependency upon their medication in terms of wanting to have access to it at all times should they have an attack:

Once I've got my oxygen, I'm quite happy, you know. I know I've got my oxygen with me. I've got a bit of a panic in me if I'm out and I haven't got my tablets or my oxygen, then I think I have to get home, I have to get back because if something happens then I'm struggling here. [...] My wife always has a little emergency bag in her handbag with a couple of little tablets in. I can't always take my oxygen with me wherever I go, but I've always got tablets on me 24/7, three hundred and sixty-five days a year because I never know when the bouts gonna strike. – P4, M, 40-60, Episodic

Most participants described adopting a 'trial-and-error' approach where they tried several different treatments in order to find one that worked for them, with varying degrees of success. As part of this, they also discussed the trade-off that they had to make in terms of the pain relief that they get from taking various treatments, and the side effects that they have to face as a result:

I won't feel very well because of the Verapamil because that makes my heart basically it just makes me quite faint because obviously it lowers my blood pressure too much basically. Um, and yeah so, I just generally feel rubbish. [...] Um, I do worry that obviously the amount of Verapamil that I take when I'm really suffering might negatively, you know, impact my actual health in a different way. – P9, F, 25-39, Episodic

Participants also described the dilemma they faced with their current medication around how they cannot treat all of their attacks. Several participants described the fact that they are limited in how many injections they can take in a day, and therefore often ration their medications, feeling like they have to 'save' them for the most extreme attacks:

The Sumatriptan shots do work but because you can only take a maximum of two a day, you have to be very selective about when you use them because if you're getting four to six attacks a day and you can only beat two of them with shots, that still leaves a few that you've got to try and manage in a few ways, usually with oxygen. So usually what happens is I try and save the shots for when I wake up and one is full blown, or when I'm at work and I can't get to the tank because I'm in a meeting or whatever. – P10, M, 25-39, Episodic

Participants also described difficulties accessing repeat prescriptions from GPs, and indicated this was an area where their care could be improved. The majority of participants tended to attribute it to GPs being wary of over-prescribing due to the cost. This added to participants feeling that they needed to 'save' their treatments, and suffer without being able to take anything:

So, I have to request the injections and I'll request fourteen so for a week's supply. That has to then go past the receptionist, who will then only probably get the doctor to prescribe me eight. Then they have to be ordered in, so by the time I go and pick them up I have to give them another prescription while I'm picking the other ones up, it's just silly. So, that's



frustrating. [...] I know my own body and I know if I'm going to need fourteen injections a week, I should be given fourteen injections for a week. – P5, F, 40-60, Episodic

Conclusion and recommendations

In particular, the study findings indicated that more needs to be done in two key areas: 1) Raising awareness of the disorder and its real impact among the general public and medical profession 2) Extending care beyond treatment, supporting patients in self-management and navigating its impact on their mental health and social life.

The findings suggest that better training for GPs is required to improve their awareness and create a more sensitive understanding of the condition. In addition, more proactive care in terms of providing treatment and sufficient repeat prescriptions would lead to immediate improvements in the management of cluster headache.

The study findings also suggest that at present, the care for cluster headache patients in the UK is too limited in focus. The majority of participants described how for them, it is primarily based on providing treatment, with little support offered beyond this. The study data, however, indicated that the day-to-day decisions that cluster headache patients make, such as around trigger avoidance, have a large impact on their headache management and overall health. As a result, care that is based on treatment alone is not sufficient. To address this, the findings suggest that GPs in particular should work in partnership with patients to support them in their self-management. This could involve offering advice alongside behavioural management interventions tailored to their individual needs. Furthermore, psychological support should also be considered as a potential element of cluster headache care to help address the real impact that it can have on their mental health.