

Years of needless pain

Misdiagnosis and lack of referral to specialists prevents people with cluster headaches from getting the help they need, says Ashley S. Hattle.

The first time I experienced a cluster headache, I thought I was dying. I thought it was an aneurysm or stroke, because surely this amount of pain would kill me. But then, after around 90 minutes, it was gone, leaving my body drained and my mind full of fear.

Cluster headache is one of the most painful conditions people can experience. Those who have felt it rate the pain as considerably worse than that from childbirth, kidney stones and gunshot wounds. It is not like any other kind of head pain; it is a different beast entirely. However, when people like myself head to the hospital or to our physicians, we rarely get the help we need. Medical professionals commonly chalk up the pain as a migraine attack – a misdiagnosis that can take years or even decades to correct, meaning a long wait before effective treatment can finally be prescribed.

I was told for six years that I couldn't have cluster headaches because I am a woman, and cluster headache is most common in men. My symptoms were dismissed by several clinicians. I relied on sumatriptan for relief. The drug helped to stop attacks in progress, but it cost US\$215 for just two injections and came with severe side effects that I would not understand fully until my early 30s, when tests revealed evidence of a possible heart attack. Had I been offered other forms of treatment sooner, such as oxygen therapy, I could have avoided some of these injections.

As my cluster-headache attacks became more frequent, I searched for answers, desperate to learn as much as I could about the condition. Finding little to no information available for patients, I began work on a textbook for people like me who were encountering uninformed medical professionals and not receiving the right treatment. But patients should not have to become experts in their own condition.

Missed opportunities

Cluster headache affects nearly 1 in 1,000 people worldwide and is almost three times more prevalent in men than in women. Attacks come on quickly, peaking within a few minutes, and produce strictly one-sided facial symptoms, such as a red, watery eye and stuffy or runny nostril on the affected side, along with forehead sweating. The pain is often described as a red-hot poker or ice pick stabbing behind the eye and on the temple. Attacks can happen up to eight times a day, often at regular times within a 24-hour



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period – including while asleep. Colloquially, it is referred to as suicide headache.

It is a horrendous condition to live with, and it is made worse by the unnecessary barriers that people encounter when they try to seek help. Those who go to their general practitioner (GP), ear, nose and throat specialist, ophthalmologist or dentist with episodic or chronic cluster headache are commonly misdiagnosed with migraine, sinusitis, trigeminal neuralgia or jaw disease. It takes 2.6 years on average to get an accurate diagnosis in the United Kingdom, 5.3–6.4 years in Italy and Eastern Europe, and 6.6–8.5 years in the United States (A. Buture *et al. Neurol. Sci.* **40**, 25–39; 2019).

The lengthy wait for an accurate diagnosis has severe consequences. The treatment is different from that for migraine. Although sumatriptan is used to relieve attacks in both conditions, it is effective in people with cluster headaches only if it is injected – the oral version used to treat migraine works too slowly to be useful. A person misdiagnosed with migraine will also miss out on oxygen therapy, and might receive other ineffective oral medicines such as opioids, which can cause dependency problems.

Improving care

The main barriers to the appropriate diagnosis of cluster headache are the physicians' failure to ask the correct questions and reluctance to refer patients to a specialist. I, like many others, have faced these issues, forcing us to advocate for proper care and search for qualified physicians who will listen without bias.

If clinicians fail to ask their patients how severe the pain is, where it's located, how long it lasts and how frequently it strikes, they are unlikely to make the correct diagnosis. Furthermore, if the questions are never asked, the information will not appear in the patient's medical records – meaning that even if a headache specialist were to review the case, they would find nothing to alert them to the possibility of misdiagnosis.

In a study designed to explore clinicians' understanding of cluster headache in northern England, researchers found that GPs were aware of the severe impact the condition has on quality of life (A. Buture *et al. Br. J. Gen. Pract.* **70**, e514–e522; 2020). GPs also showed an understanding of how the condition was misdiagnosed and mismanaged. However, they admitted they were still hesitant to refer patients to secondary care – perhaps because of the cost or long waiting times. When referrals were made, it was because the patient pushed for it. The study also found that GPs would sometimes overrule the treatment recommendations of specialists in favour of a cheaper alternative.

The reluctance to refer to secondary care, the high rate of misdiagnosis and the lack of treatment causes unfathomable pain: in a survey by the support group Clusterbusters, 69% of nearly 2,000 people with cluster headache reported having suicidal thoughts during untreated attacks. It is unethical and unnecessary for people with this condition to face years of misdiagnosis and mismanagement when cluster headache is so readily identifiable. If physicians listen to patients' descriptions of their attacks and refer them to specialists, the lives of people with cluster headaches will be changed immeasurably for the better.